

Editorial

Aloha Means Hello and Goodbye

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Review of Disability Studies: An International Journal Editor-In-Chief

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In the summer of 2001 I was a new faculty member at the Center on Disability Studies (CDS), University of Hawai'i, literally fresh off the boat from Berkeley, California and still calling myself "Dr. Conway" with awe and pride after years of pursuing my doctorate-or-die. I was chipper, passionate and dumb. I landed in Hawai'i as all Haoles do with preconceived and completely wrong ideas about life in Paradise and an irrational fear of giant cockroaches. And as a disabled white woman from the land of Crip Freedom and Pride, I was also in for an additional shock when confronted by prejudice and inaccessibility. Complaining about my rights under the Americans with Disabilities Act got me nothing but mute stares, mulish put offs and a muttered "show some Aloha." You think?

I came onboard CDS to coordinate a federal grant focused on transition, but my somewhat (at the time) hidden passion was Disability Studies. I had nabbed the job at CDS partly via a connection between my Berkeley mentor Susan O'Hara and longtime Disability Studies Quarterly (DSQ) Editor David Pfeiffer, who was settling into semi-retirement in Hawai'i and was pleased to have me increase the number of faculty with disabilities at CDS from 1 to 2. We were soon joined by fellow Cripstar Steven Brown, and felt ourselves almost overrepresented at our center then comprised of 100 faculty and staff.

By 2003 David had been forced (by his account) to relinquish his editorship of DSQ and had decided to start a new journal, the Review of Disability Studies: An International Journal, with me and Steve as Assistant Editors. I was excited by the prospect of learning about academic publishing and the wild world of Disability Studies under David's tutelage. And then David died. I did not know David well personally, just had a great deal of respect for him professionally, but I do remember watching the canoes paddle out with his ashes on board thinking, quite selfishly, "now what"?

Now what was the [inaugural issue of RDS](#), published in December of 2004, conceived of and assembled by David and executed with great enthusiasm and limited experience by Steve and me. It was a gargantuan issue, with 27 articles, essays, creative works, book reviews and notes from the field. Contributors (in addition to the three noble editors) included legends and novices, the now living and the now passed: Mark Sherry, Reiko Hyashi & Mariko Kimura, Mary Fleming & William Ross, Adam Corrico & Leonard Jason, Jennifer Coles, Janice Dewey & Megan OHare, David Connor, Beth Omansky, Alex Lubet, Steven Gilson & Elizabeth DePoy, Mark Medoff, Jillian Weise, Tanis Doe, Ottmar Paul, Jean Johnson and Steven Taylor. I really have no idea how or why we put together such a big baby, but it was a good baby and the beginning of a creative project that has sustained me through professional hardships and joys for the past 15 years.

As you may have guessed by now, I am leading up to a goodbye. After 18 years with the University of Hawai‘i and 15 years in various editorial roles with RDS culminating with Editor-In-Chief, I am heading back to California and handing over the reins of RDS to someone new. The baby is now a teenager and ready to try new things. I know that our wonderful Editorial Board, Review Board, Editorial Assistant, and new leadership will keep a steady course and maintain RDS’ relevance in the ever growing field of Disability Studies. I leave the particulars of the “now what” for the new Editor.

If you have made it this far in my monologue about the humanization of an academic journal, you might be curious to know what I am doing next. I am leaving academia for a bit, or forever, time will tell, to work in the “real world”. Sometimes we have to move back to move forward. Sometimes we have to say goodbye to say hello.



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Research Article

Autism in Saudi Arabia: Present Realities and Future Challenges

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Abstract: Despite improvements in the services provided to individuals with autism, some third world countries continue to struggle to provide services to individuals with autism. In this paper, the impact of culture on people's understanding of autism in the Kingdom of Saudi Arabia (KSA) is highlighted, as well as how its influence impacts the provision of necessary supports needed by individuals with autism. Using a historical context, the paper outlines the unique challenges presented by the culture and how these contribute to difficulties government agencies encounter in providing children with autism and their families with services.

Keywords: Autism; Disability; Special Needs; Culture; Service; Kingdom of Saudi Arabia

The social conception of disability has been a topic of discussion across many countries and cultures with one major concern and challenge being how to best meet the needs of people with disabilities. With recent developments in technology and healthcare in many developed countries, knowledge and treatment interventions for diseases and genetic conditions have increased. However, developing countries are still working to improve their health sectors in an attempt to address the challenging health issues faced by their citizens, and disability is among the many issues with which they continue to struggle.

The number of people with disabilities is rapidly growing in some countries. According to the World Health Organization (WHO, 2011), prevalence rates in low income countries was 11.8% as compared to 18% in high income countries, when measured by 2004 gross national income per capita. "The burden of childhood disability as a public health problem in these areas of the world remains relatively unrecognized" (Shawky, Abalkhail, & Soliman, 2002, p. 61).

In some cases, the development of special education in third world countries has been slow and challenging. Prior to 1958, in the Kingdom of Saudi Arabia (KSA), parents had full responsibility for caring for their disabled children (Alquraini, 2011). In 1958, some students who were blind or had visual impairments began receiving educational services in schools referred to as scientific institutes (Salloom, 1995). Later, in 1962, the Department of Special Learning was established by the Ministry of Education and has since been providing educational and rehabilitation services for individuals who are blind, deaf, and those with a range of cognitive abilities (Al-Kheraigi, 1989; Alquraini, 2011).

Cultural values and beliefs may impact the development and delivery of services for disabled children. Specifically, Al-Jadid (2013) suggests difficulties associated with research related to the current conception of disabilities in Saudi Arabia include shame, a lack of understanding of the causes of disabilities, and a reluctance to use the term disability, in

attempts to protect individuals and their families from potential stigma. In some cases, traditional and less scientific views regarding the range of abilities and needs (Alqahtani, 2012; Ravindran & Myers, 2012), can impede early diagnosis and intervention. One of the most challenging issues encountered by experts, families, and policy makers, is the growth in the number of individuals being diagnosed with autism spectrum disorders (ASD).

Similar to other socially constructed limiting conditions, individuals with ASD require special supports and services. Students with autism can exhibit “communication and language deficits, cognitive disorders, sensory processing deficits, and stereotyped behavior” (Webber & Scheuermann, 2008, p. 3). Therefore, in the current environment in the KSA, providing accommodations, services, and the necessary treatments can be demanding and stressful for family members (Zeina, Al-Ayadhi, & Bashir, 2014) and service providers (Al-Jadid, 2013).

Not only families, but, special education professionals encounter unique challenges associated with the current understanding and provision of services related to autism (Taha & Hussein, 2014). In addition to the ongoing search for causes of autism, the controversy over treatment options, and the range of services provided to individuals with autism have sparked many heated debates. There is a continuing disagreement over whether the treatment options are worthy of investment, and whether healthcare companies should cover the full range of treatments for individuals with autism. Specifically in the United States, there are debates about whether health care companies should pay for medical coverage for disabled individuals, the effectiveness of medications and other treatment options, and the specific causes of autism; while third world countries still struggle with more basic issues of services for individuals with autism (Taha & Hussein, 2014). This paper identifies issues related to the diagnosis of autism and provision of services for individuals diagnosed with autism in the Kingdom of Saudi Arabia. Additionally, we describe how services for individuals with autism have been viewed by those in the field of special education within the Saudi context.

Despite its status as a relatively new field in Saudi Arabia, special education services have improved in the last decade. This article examines how the improvements have specifically affected individuals with autism. To provide the necessary context, we begin with a brief description of Saudi Arabia, highlighting the major social, political, and geographical aspects of the country. Next, we examine how autism is understood and defined in Saudi Arabia and how this definition impacts the ability of government agencies to provide the necessary services for individuals with autism. To understand the challenges that government agencies face in Saudi Arabia, a historical overview of the improvements that have been made, provide a context for the current state of available services for individuals with autism. We explore and critique the services available to individuals with autism in Saudi Arabia, providing insights into the pace of service development. Finally, we make recommendations based on the current knowledge and within the contextual limitations of the Kingdom of Saudi Arabia.

Autism is characterized by differences in social-emotional reciprocity such as in back and forth conversation, limited sharing of emotions, interests, affect and response, and the

apparent absence of initiation of social interaction. Children with autism may also experience differences in motor coordination, intellectual disability, attention, and physical health issues such as gastrointestinal disturbances and sleep disorders (American Psychiatric Association, 2013).

Saudi Arabian Context

The Kingdom of Saudi Arabia is located in Western Asia in the Middle East and occupies approximately 80% of the Arabian Peninsula between the Persian Gulf and the Red Sea. It is bordered by Jordan, Iraq, Kuwait, the Persian Gulf, Bahrain, Qatar, the United Arab Emirates (UAE), Yemen, and Oman. It is populated by over 33 million people (United Nations, 2017), and despite its immense oil wealth still “faces enormous problems of access to health care” (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009, p. 341; Salhia, Al-Nasser, Taher, Al-Khathaami, & El-Metwally, 2014).

Due to inconsistent availability of health and specialized care in developing countries, many conditions are often overlooked that would typically be identified in developed countries (Salhia et al., 2014). This can be attributed to several factors, including a limited availability of services, inexperience with identification, lack of exposure to specific conditions, and a “lack of appropriate training among in professionals” (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009, p. 345).

Beliefs of Causes

According to survey results reported by Almana, Alghamdi and Al-Ayadhi (2017), the majority of Saudis have heard about autism and have some general knowledge of it. Their results indicated that the Saudi community paid less attention to the organic causes of autism, as they believe it to be a psychiatric process. Only a few identified pregnancy complications as the cause, and most believed that with proper intervention, children with autism could outgrow it.

Research supports an association between autism and parental age, as parental age increases the risk of having a child with autism increases (Salhia et al., 2014). Delayed speech is the first noted characteristic among children diagnosed by child psychiatrists, and speech, behavioral, and pharmacological therapies are the most used therapeutic interventions for Saudi children diagnosed with autism (Al-Zaalah, Al-Asmari, Al-Malki, A-Shehri, & Al-Moalwi, & Mostafa, 2015).

While most Saudi people have some general knowledge of autism, there is much confusion surrounding its organic causes. Since the Department of Special Education and Saudi Arabian government are ensuring students with disabilities receive special education, it is important that more awareness about autism be widely disseminated to ensure more students receive special education services and parents receive necessary supports.

Prevalence

While exact figures are not available, anecdotal reports suggest an increase in the prevalence of autism in Saudi Arabia. One recent report estimated that there were 42,500 confirmed cases of autism in 2002 and that many more remained undiagnosed (Al-Salehi, Al-Hifthy, & Ghaziuddin 2009, p. 341).

Based on a sample of 49 consecutive referrals to a teaching hospital in Riyadh, Saudi Arabia in an early prevalence study, Al-Salehi, Al-Hifthy, and Ghaziuddin (2009), determined males outnumbered females by a ratio of 3 to 1, using the 1994 DSM criteria for the diagnosis of autism. Additionally, they reported that age of onset was likely before 3 years of age, however, they were not able to substantiate this assumption due to limited available information. They did note that females were older when evaluated. A more recent systemic review by Salhia and colleagues (2014) reported prevalence rates that ranged from 1.4 to 29 per 10,000 people in the region. In a review of literature from member countries of the Gulf Cooperation Council (GCC) in the Middle East, which includes the KSA, Kelly et al., (2016) reported lower prevalence rates when compared to western countries, however, the discrepancy may be due to underdiagnosis and reporting in Saudi Arabia (p. 160).

The GCC regional prevalence estimates differ from those reported by the Center for Disease Control and Prevention which indicate that in the United States, 1 in 68 or 14.7 per 1,000 children aged 8 years or older have been diagnosed with autism. Gender studies indicate that 1 in 42 boys and 1 in 189 girls have been diagnosed with ASD (Li, Fallin, Riley, Landa, Walker, Silverstein, & Hong, 2016).

Support for Autism

In 2004, the Saudi government began developing special education services by investing in research and encouraging universities to open special education programs to train professionals capable of providing services to those in need (Prince Salman Center, 2004). While this has been the case, all disabled individuals have not received the same levels of attention in Saudi Arabia, with those diagnosed with autism among them. In fact, in 1993, private individuals initiated the first program for individuals with autism (Al-Aoufi, 2011, p. 9). It was not until 2004 that the government started its first program serving those diagnosed with autism.

Within public schools in Saudi Arabia, the special education department has opened special schools which care for children diagnosed with mild to moderate intellectual disabilities. Other students included in the program include those with autism and hearing impairment (Aldabas, 2015). Such schools provide students with special education services and resources. Moreover, the government has passed several laws to ensure that disabled students receive an appropriate and free education (Aldabas, 2015). Although serving individuals diagnosed with autism has recently received more attention, it remains a major challenge the government, special education professionals, service providers, and families must address.

With the initiation of government-sponsored programs, policy makers created an avenue for families to receive services for their autistic children with centers specifically designed to provide diagnosis, intervention, and support. As demonstrated in the literature, the impact and importance of early diagnosis and intervention is critical for children with a variety of disabilities, including autism (Corsello, 2005). When detected at an early age, early interventions that address the symptoms and characteristics of autism are incredibly fruitful. Al-Aoufi (2011) states, “Children with developmental delay who are exposed to early intervention programs are more likely to gain more coping strategies than later in life” (p. 72). Early intervention programs are useful for providing both diagnoses and strategies that promote a more positive long-term outcomes for children.

Benefits of Governmental Programming

Early Intervention

One of the Saudi government’s most significant efforts related to autism, was to create early intervention programs. Recognizing the importance of early intervention, the Saudi government established intervention programs to help both individuals with autism and their families. As with any new initiative, there are supporters as well as critics. Supporters applaud the interdisciplinary nature of services, early diagnostic services, and benefits of parental training, which are addressed in the following sections.

Interdisciplinary service

Those in favor of early intervention programs for individuals with autism tout their interdisciplinary nature. Al-Aoufi (2011) notes, “Early intervention is multi-disciplinary service, where more than one intervention approach or service could be provided for the child and the family as required” (p. 71). The interdisciplinary nature is meant to address the range of abilities related to autism by providing, “psychological services, diagnosis and assessment, consultations, transportation, family training, occupational therapy, speech therapy, dietary therapy, medication therapy, behavioral modification therapy and play therapy” (p. 71).

Diagnosis

The early intervention programs established by the Kingdom of Saudi Arabia also provided increased access to diagnostic services. The availability of these services ensures the detection of a range of disabilities at an early stage. Once a diagnosis is made, professionals can begin to develop an individualized strategy designed to support the individual’s unique needs. Proponents are hopeful the government will expand its programming to address the needs of more individuals and disabilities across all parts of the country (Alotaibi & Almalki, 2016; Alquraini, 2011). As proposed by Al-Aoufi (2011), the Saudi government must continue to establish additional special education programming that would provide services to individuals with special needs in general, and individuals with autism in particular (p. 50).

Parent training

Another beneficial service related to autism provided by the Saudi government is that of parent training. Supportive of findings from Alotaibi and Almalki (2016), who reported

parents' primary concern was a need for information, early intervention programs in Saudi Arabia contain a component to help train parents of children with autism to address their range of abilities and develop strategies to support their children's development. These programs also provide children with therapies, "to remedy current developmental problems, in order to stop its re-occurrence and to provide the families with an action plan in order to help these children" (Al-Aoufi, 2011, p. 7). Interestingly, the 80 parents who participated in the Alotaibi and Almalki (2016) study, rated a need for information greater than a need for support or community services.

Challenges of Governmental Programming

As previously mentioned, there has been some criticism of the development of government-sponsored services for individuals with diagnosed conditions. Criticism focuses on a lack of access to services, limits on the number of individuals that can be served, delays in diagnosis, and limited knowledge which are addressed in the following sections.

Lack of Access

While many individuals have been able to take advantage of government-sponsored diagnostic services, others have been critical of the limits associated with these services related to autism. Al-Masoud (2011) points to an inability to accurately diagnose autism due to classroom teachers and parents' inability to recognize the hallmark characteristics of ASD. Additionally, even though efforts have been made to provide diagnostic services through early intervention programs, the process can still be confusing which limits its effectiveness. Moreover, with the increasing number of individuals being diagnosed with autism, additional challenges can be anticipated.

Limited Availability of Services

Unfortunately, once an individual is assessed and diagnosed, there is no guarantee services will be available. Al-Aoufi (2011) reports, "The number of individuals accommodated is minimal compared to the existing number of individuals with autism" (p. 51). Despite the best intentions of policy makers, limited access to services has posed a challenge and has been one of the major barriers for early intervention programs (Alotaibi & Almalki, 2016; Salhia et al., 2014). With the increasing numbers of people diagnosed with autism and continuing issues of access to services, there is a need to expand capacity and expertise to provide services to ensure the success of special education intervention programs for individuals with autism and broaden their reach.

Delayed Diagnosis

As previously noted, the earlier a diagnosis is made, the more positive the outcomes, due to professionals' abilities to identify key issues and develop a clear plan of action to mitigate or eliminate the negative impacts. Seif Eldin, Habib, Noufal, Farrag, Bazaid, Al-Sharbati, Bader, Moussa, Essali, and Gaddour (2008) describe autism and the long-term

challenges delays in diagnosis can cause. They posit these delays “in many Arab countries has led to excess impairment and burden to affected children and their families” (p. 281).

In addition, early intervention services can also be complicated by inaccurate diagnoses. Autism is often misdiagnosed in Saudi Arabia when compared to other physical and mental conditions (Alqahtani, 2012, p. 15) which can lead to delayed or ineffective interventions. Additionally, the diagnosis process is not always clear. Al-Aoufi (2011) reports that, “participating mothers expressed specific concerns about the confusion over diagnosis” (p. 291). Such confusion can also lead to delays in the provision of services, resulting in less than optimal progress for children diagnosed with autism.

Limited Knowledge

A lack of informed public regarding autism can be challenging and have adverse consequences. Alqahtani (2012) asserts that, “The lack of information about autism among parents may contribute to a failure to provide appropriate treatment and help” (p. 15). With no or even limited knowledge about autism, parents may rely on a cultural (i.e., unscientific) understanding of physical and mental disabilities. Frequently, a lack of information also leads to a reliance on informal treatments. For instance, Alqahtani reported that many of the females interviewed in his study believed the causes of autism to be cultural, resulting in treatments based upon cultural beliefs. In these cases, culturally-based treatments are viewed as the appropriate way to treat autism because of a lack of parental knowledge regarding autism. To these individuals, “Informal treatments are chosen because they are perceived as healing the source of symptoms rather than the symptoms themselves” (p. 21).

Additionally, as is still the case in many western contexts, it is clear from the language used in the literature that the KSA still holds to a medical model of disability. Disabled individuals (Barclay, 2017) are still considered in need of medical intervention. Until social conceptions of the range of abilities within the disabled community are addressed, true inclusive approaches and alternative perspectives will have limited traction.

Limited Resources

While government-sponsored intervention programs are purported to help educate families with individuals with special needs, a lack of available professionals in these intervention programs has been a major challenge. While professionals are supposed to provide support in this regard, Al-Aoufi (2011) found the “internet was the parents’ first choice to obtain information about autism and its treatment” (p. 290).

Finally, Al-Aoufi (2011) outlined additional challenges that face early intervention programs in Saudi Arabia. Such challenges included the (a) limited collection and use of accurate statistics on the number of individuals with disabling conditions, including those with autism; (b) shortage of experts and qualified professionals to develop effective services and the ability to work efficiently with individuals with disabling conditions; (c) limited programs for raising the general public’s awareness about disabling conditions, their causes

and methods of prevention and remediation; (d) lack of local research within the disability field; and (e) the lack of an organized training and counseling program that offers education and support for families of individuals with disabilities.

External Obstacles to Governmental Efforts

The shortcomings of intervention programs in Saudi Arabia have been identified and delineated, however there are additional factors that may play a role in the effectiveness of government-sponsored programs that are outside of its control.

Cultural Issues

It is common for each culture to have its own response to unfamiliar conditions, disabilities, and diseases (Alqahtani, 2012; Zeina et al., 2014). Some within the Saudi culture, being less familiar with the causes of autism, have attributed autism to superstitious causes, which has impacted efforts to improve the quality of special education services. The beliefs and practices regarding the potential and treatment of individuals with autism are different from one culture to another and change over time (Ravindran & Myers, 2012). Culture influences key aspects of the diagnosis and treatment process and affects the likelihood that individuals seek help, what treatments to use, available resources, and relationships between families and professionals. Daley (2002) suggests the treatment approaches that work and are culturally accepted in the West may not be the same approaches accepted and used to treat children (or adults) with ASD in other parts of the world.

In the West, potential causes of autism are identified based on science, and various treatments are available which include behavioral, cognitive, pharmaceutical, sensory, relational, vitamins, and diet therapy. However, in other cultures, the causes of autism might be still regarded as 'Karma, 'Allah's will,' or 'the will of God' which results in non-scientific treatments such as acupuncture and/or herbal medicine (Kelly et al., 2016; Ravindran & Myers, 2012).

Lack of Research

Improvements in intervention programs require research exploring the effectiveness of these programs. In Saudi Arabia, a lack of research contributes to the lack of quality services provided to individuals with autism (Kelly et al., 2016). Al-Salehi and Ghaziuddin (2009) found that deterioration in the quality of services provided to individuals with autism can be attributed to an under-representation of topics such as autism, addressed in child psychiatry publications. The lack of research on ASD has created a major challenge in efforts to evaluate and improve the services provided to individuals with autism. With additional research, the government could generate accurate prevalence rates, analyze effective interventions, and provide suggestions for how intervention programs can be improved and expanded, thereby achieving their stated goal of improving outcomes for individuals diagnosed with autism.

Recommendations

The Saudi government has experienced challenges in providing supports and services to individuals diagnosed with autism. Despite recent efforts, there is a need for more research and improved services. Without research into the efficacy of supports and services, the ability to make evidence-based decisions and recommendations is limited. Research evaluating the system of supports and services can identify shortcomings of intervention programs and support new developments addressing the needs from those most closely involved.

There is also a need for more investment in the recruitment and training of professionals to ensure that individuals with autism are receiving timely and appropriate services. Additionally, intervention programs can make use of new technologies to improve services. Creating a database of information regarding the characteristics, potential causes, available services for individuals with autism, and advice for parents whose children have been diagnosed or may be at-risk for autism, can help educate the general population about autism.

The Internet has been useful in supplying information about other physical conditions and disabilities. Abo El-Soud, Hassan, Kandil, and Shohieb (2010) describe websites that “are especially developed for disabled persons. Some of these websites are e-learning application for the disabled people” (p. 56). Additional recommendations include the distribution of an “e-learning module that was developed to support library staff training in disability awareness” (p. 56). Technology would also be beneficial in this regard to facilitate training for both professionals and family members.

Finally, to address the social construction of disability which underpins attitudes towards individuals diagnosed with autism and perpetuates conditions that serve to disable rather than enable, the KSA should adopt a more aggressive stance and promote inclusive environments and practices. Principles of Universal Design for both the environment (Iwarsson & Ståhl, 2009) and for learning (Rose & Meyer, 2006) should be adopted and implemented across the Kingdom, combined with an informational, social media blitz to increase understanding of the range of abilities that exist in society and how individuals can encourage full participation of all citizens.

Conclusions

Despite the efforts of Saudi Arabian government-supported programs and the support such programs have provided to individuals with autism and their families, these programs still have a long way to go. Experts have criticized governmental programs for delayed diagnoses, misdiagnoses, limited availability of services, and a lack of knowledge of the general public. Despite the criticisms, anecdotally, government-sponsored intervention programs still provide some positive outcomes for those who are able to access their services and are worthy of praise. Addressing their shortcomings coupled with the adoption and encouragement of a more inclusive approach to the full range of abilities, will enhance the available services and subsequently improve outcomes for individuals diagnosed with autism

in Saudi Arabia and their families.

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References

- Abo El-Soud, M., Hassan, A. E., Kandil, M. S., & Shohieb, S. M. (2010). A proposed web-based framework e-learning and dictionary system for deaf Arab students. *International Journal of Electrical & Computer Sciences*, 10(1), 56–69.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Al-Aoufi, H. (2011). *An investigation into issues related to the establishment of a parental training course to develop an early intervention home-based program for children with autism*. Unpublished doctoral dissertation, Brunel University, Uxbridge, Middlesex, England.
- Aldabas, R. A. (2015). Special education in Saudi Arabia: History and areas for reform. *Creative Education*, 6(11), 1158.
- Al-Jadid, M. S. (2013). Disability in Saudi Arabia. *Saudi Medical Journal*, 34(5), 453–460.
- Al-Kheraigi, F. S. (1989). *Special education development in the Kingdom of Saudi Arabia from 1958 to 1987*. Unpublished doctoral dissertation, Syracuse University, Syracuse.
- Almana, Y., Alghamdi, A., & Al-Ayadhi, A. (2017). Autism knowledge among the public in Saudi Arabia. *International Journal of Academic Scientific Research*, 5(1), 198–206.
- Al-Masoud, H. (2011). *Enhancing public services for individuals with autism in Saudi Arabia*. Unpublished manuscript, King Saud University, Riyadh.
- Alotaibi, F., & Almalki, N. (2016). Parents' perceptions of early interventions and related services for children with autism spectrum disorder in Saudi Arabia. *International Education Studies*, 9(10), 128–140.
- Alqahtani, M. M. J. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, 10(1), 15–22. doi:10.3233/JPN-2012-0527.
- Alquraini, T. (2011). Special education in Saudi Arabia: Challenges, perspectives, future

- possibilities. *International Journal of Special Education*, 25(3), 139–147.
- Al-Salehi, S. M., Al-Hifthy, E. H., & Ghaziuddin, M. (2009). Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. *Transcultural Psychiatry*, 42(2), 340–347.
- Al-Salehi, S. M., & Ghaziuddin, M. (2009). G6PD deficiency in autism. *European Child & Adolescent Psychiatry*, 18(4), 227–230.
- Al-Zaalah, M. A., Al-Asmari, A. H., Al-Malki, H. H., A-Shehri, N. M., Al-Moalwi, N. M., & Mostafa, O. A. (2015). Characteristics of autism spectrum disorder among Saudi children and its impact on their families. *Neurologist*, 31, 239–244.
- Barclay, J. L. (2017). “Differently abled: Africanisms, disability and power in the age of transatlantic slavery.” In J. F. Byrnes & J. L. Muller (Eds.) *Bioarchaeology of impairment and disability: Theoretical, ethnohistorical and methodological perspectives*. New York: Springer.
- Corsello, C. M. (2005). Early intervention in autism. *Infants & Young Children*, 18(2), 74–85.
- Daley, T. C. (2002). The need for cross-cultural research on pervasive developmental disorders. *Transcultural Psychiatry*, 39, 531–550.
- Iwarsson, S., & Ståhl, A. (2009). Accessibility, usability and universal design-positioning and definition of concepts describing person-environment relationships. *Journal of Disability and Rehabilitation*, 25(2), 57–66.
- Kelly, M. P., Alireza, I., Busch, H. E., Northrop, S., Al-Attrash, M., Ainsleigh, S., & Bhuptani, N. (2016). An overview of autism and applied behavior analysis in the Gulf Cooperation Council in the Middle East. *Journal of Autism and Developmental Disorders*, 3, 154–164.
- Li, M., Fallin, M. D., Riley, A., Landa, R., Walker, S. O., Silverstein, M., ... & Hong, X. (2016). The association of maternal obesity and diabetes with autism and other developmental disabilities. *Pediatrics*, 137(2), e20152206.
- Prince Salman Center for Disability Research. (2004). *Kingdom of Saudi Arabia provision code for persons with disabilities*. Riyadh, Saudi Arabia: Prince Salman Center for Disability Research.
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21, 311–319. doi:10.1007/s10826-011-9477-9
- Rose, D. H., & Meyer, A. (Eds.). (2006). *A practical reader in universal design for learning*. Cambridge, MA: Harvard Education Press.
- Salhia, H. O., Al-Nasser, L. A., Taher, L. S., Al-Khathaami, A. M., & El-Metwally, A. A. (2014). Systemic review of the epidemiology of autism in Arab Gulf countries. *N Neurosciences (Riyadh)*, 19, 291–296.
- Salloom, I. H. (1995). *Education in Saudi Arabia* (2nd ed.) Beltsville, MD: Amana Publications.

- Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbaty, M., Badr, H., Moussa, S., Essali, A., & Gaddour, N. (2008). Use of m-chat for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry*, 20(3), 281–289.
- Shawky, S., Abalkhail, B., & Soliman, N. (2002). An epidemiological study of childhood disability in Jeddah, Saudi Arabia. *Pediatric and Perinatal Epidemiology*, 16, 61–66.
- Taha, G. R., & Hussein, H. (2014). Autism spectrum disorders in developing countries: Lessons from the Arab world. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.), *Comprehensive guide to autism* (pp. 2509–2531). Springer New York.
- United Nations DESA Population Division. (2017). *World population prospects 2017*. Retrieved January 30, 2018 from <https://esa.un.org/unpd/wpp/>
- Webber, J., & Scheuermann, B. (2008) *Educating students with autism: A quick start manual*. Texas: Pro. Ed.
- Zeina, R. M., Al-Ayadhi, L., & Bashir, S. (2014). Autism spectrum disorder: Main problem waiting for solution in Kingdom of Saudi Arabia. *Autism*, 8(8), 487–490.

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Research Article

Playing with Normalcy: A Disability Material Culture Analysis

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Abstract: We recast a toy figure as a cultural agent of various interlocking and hegemonic discourses, and in particular, explore how normative discourses are reflected in material objects. We suggest that the Toy Gymnast represents and reinforces these discourses and therefore influences how children learn that normative bodies are desirable.

Keywords: Disability; Toy; Childhood

Introduction

We play with them and learn from them, but as pedagogical artifacts, toys are much more than just playthings. In this paper, we explore the significance of toys in educating disabled children about their bodies and their agentic capacities. We explore the role of toys as cultural and pedagogical agents of interlocking and hegemonic discourses. In particular, we focus our analysis on the normative and eugenic discourses in a single child's toy – the Toy Gymnast. Through a historical analysis of the representation of “ideal/normal” bodies in this toy, we illuminate how these discourses infiltrated a variety of cultures and continue to be embedded in everyday and commonplace objects. In exploring disability in an object often unassociated with experiences of difference, we seek to demonstrate the potential and complexity that a Disability Studies perspective provides to the analyses of everyday objects. Here, we follow Ott's (2014) claim that disability material culture is found everywhere – and thus, in everything.

During the course of our research in 2011, we discovered the toy among a collection of materials from one participant (who we have given the pseudonym Lynn) who was part of a larger project on the experiences of Canadian polio survivors¹ (Yoshida & Shanouda, 2015; Yoshida, Shanouda & Ellis, 2013). In attempting to preserve memories of their time in the hospital or the rehabilitation center, participants, in addition to keeping iron braces and other medical materials, also intentionally kept items that might be similar to those collected and stored by non-disabled adults: stuffed teddy bears, porcelain dolls, bronzed baby shoes, photos of their younger selves, and childhood paintings and writings. We consider the relation between experiences of disability, race, gender, and heteronormativity and these childhood objects, which are often considered devoid of disability.

The Toy Gymnast (Figure 1), was a gift Lynn received when she was approximately ten years old and seeking treatment for the effects of polio in the hospital during 1949–1950.

Figure 1. The Toy Gymnast, circa 1940s. Photo credit, Karen Yoshida, 2009.



What follows is a detailed description we developed of the Toy Gymnast:

Between two thin steel A-shaped frames – with another thin steel bar between them (resembling a swing set) hangs a white, plastic, male figure. His hat, hair, face, shirt, pants, and shoes are painted on. His hat is red and sits flat on his head covering the majority of his blond hair. His arched eyebrows are spaced perfectly equidistant; his brown/black eyes are open. His cheeks are painted rosy and his lips are pursed. His chest is covered by a sleeveless shirt with a low neckline. The majority of the figure is made up of his legs, painted in blue, and which deceptively start under the figure's chest. The ends of the plastic figure's legs depict shoes, painted in red. The figure is symmetrical, but disproportionate. A small mechanical winder is attached to the bottom of one of the A-shaped frames. When wound, the figure spins around the bar like a gymnast.

Lynn describes her time as a child playing with the object:

I'm not sure who gave me that [the toy object] but it was given to me when I was in the hospital. And I used to, you know, just play with it quite a little bit. And I don't know; I have no idea who gave it to me. Cause I had so many things given to me at the time. But it was, you know, something I used to play with. There's a little bar at the top; you can make him go around that if it's lower, or whatever. Sometimes he just sways; sometimes he goes over the bar and things like that. That was one of the things that was given to me at the time (Yoshida & Shanouda, 2015; Yoshida, Shanouda, & Ellis, 2013).

Although she was given many things in the hospital, in response to our request Lynn selected this item as one of five of the most important objects to her during this time. The other items included a pair of salt and pepper shakers, a bride and groom doll set, and a couple of other dolls. The fact that she retained the gymnast for over 60 years confirms its significance as a cherished material object and as a vehicle for recalling memories of her time in the hospital, experiences of pain/triumph and fear/joy.

Her experiences in the hospital as a disabled person are tied to Lynn's other identities at the time, as a young, white, woman from a middle-class family. Her disability is constituted in relation to those experiences, and to the materials around her. As Ott (2014) argues, "disability depends on the person, the environment, and the activity" (p. 121). Therefore, in analyzing this disability material culture object, we are cognizant of how the toy represents dominant gendered, racialized, and heteronormative discourses. We suggest that these discourses were powerful forces that contributed to Lynn's knowledge of herself and that other participants also learned about themselves through their interactions with toys and other materials from their childhood. However, the toys also had the effect of teaching children about their agentic abilities to act upon the material objects around them.

Disability Material Culture

We approach material culture from the perspective of James Deetz (1996), an American historical archaeologist. To Deetz, material culture is not culture per se, but product. Deetz (1996) states that:

Culture is socially transmitted rules for behaviours, ways of thinking about and doing things... All such behaviour is reflected in subtle and important ways in the manner in which we shape our physical world (p. 35).

Material culture is usually linked to the study of artifacts, however, Deetz (1996) advocates for a broader definition of material culture, emphasizing how our 'world' is the product of "our thoughts, that sector of our physical environment that we modify through culturally determined behaviour" (p. 35). This definition of material culture is more encompassing and allows us to include everyday objects. According to Deetz (1996), objects such as a common pin, ceramic dishware, headstones, cuts of meat, the scientific breeding of livestock, all of these things are enacted according to culturally derived ideals.

Deetz (1996) also includes our bodies and language as part of material culture. With respect to bodies, material culture is interested in all aspects of kinesics or human motion, for example, parades, dancing, work, etc. For Disability Studies scholars, this is especially significant as the body is so often the site where disability is read. However, by including the physical-social environments that disabled people live in, we reframe disability not simply as an individual experience, but also a socially produced phenomenon. It is in the interaction with everyday objects, including the kinesics of the body, that disability is produced.

McVeigh (1996) adds to Deetz's (1996) conceptualization of everyday objects by

arguing that the insidiousness of the everyday object is in its ubiquity. McVeigh (1996) refers here to the gendered messaging communicated to women in the everyday ‘cute thing’ in Japanese culture, which he argues is pervasive. McVeigh’s (1996) conceptualization of cuteness as everywhere and, therefore difficult to locate and unpack is similar to the conditions that surround the concept of normalcy. Normalcy, as the prototypical condition of the human body and experience, is omnipresent; so much so, that to be normal is considered an optimal and attainable reality. The illusion of normalcy, that it is within one’s grasp, is one of the most powerful and insidious qualities of the concept. This message, much like gendered messaging described by McVeigh (1996), is uninterrupted and communicates beliefs about bodily ideals in everyday objects, such as toys.

Finally, the materials around us, the things we interact with, also have an impact on our understanding of the world. As Brown (2001) suggests, objects “...circulate through our lives, we look *through* objects (to see what they disclose about history, society, nature, or culture—above all, what they disclose about *us*) ...” (emphasis in original, p. 4). Like windows, objects allow us to look through them to understand something about what is happening around us, and also maybe within us. Brown (2001) also argues, however, that we often fail to contend with the ‘thingness’ of objects, until they fail to work or operate as intended. Still, in breaking, fracturing, or disintegrating, things reveal themselves to us – remind us of their value and incite us to consider our connections to them in what Brown (2001) calls, “subject-object relation” (p. 4). We contend that such reminders help us to understand how things act upon us, and how we act upon and with them.

Examinations of disability material culture exist in the extant literature. Take for example, Ott’s (2002) examination of the history of prosthetics in the U.S. and Halifax’s (2014) lyrical exploration of wearing/experiencing boots with lifts – describing it as, “the particular embodiment, that disability is embodied consciousness” (p. 7). Consider also Parrott’s (2005) exploration of the objectification and agency of decorating bedrooms and self-decorating through clothing and accessories of patients in a psychiatric unit. Both Yenika-Agbaw (2011) and Narduzzi (2013) explore how seemingly innocent representations of disabled and non-disabled characters in children’s literature are imbued with ableist discourses that privilege normative bodies often at the expense of disabled and non-normative bodies. There have also been large scale exhibitions of disability material culture. *Whatever Happened to Polio?* (n.d.), is a multimedia exhibition that tells the story of polio in the United States, including the impact of the disease on American society. Also, *Out from Under*, is an exhibit of 13 disability material culture objects, which present examples of disability struggle and resistance throughout Canadian history from the perspective of disabled people (Frazee, Church, & Panitch, 2016). This exhibit is now part of the permanent collection in the Canadian Human Rights Museum in Winnipeg, Manitoba.

Our examination, in addition to contributing to the extant literature, also invites scholars to consider objects often unassociated with disability. We hope this close examination, a treasure hunt for disability, will foster deeper analyses of the underlying political and cultural projects that constitute disability as unwanted, incomplete, and

disposable. While we could give credit to these ideas to a number of historical events, including the Industrial Revolution, the World Wars, and other contemporary global events, we suggest that the hegemonic notion of normalcy, which constitutes disability as inferior, is a result of the international reach of the eugenics project.

The Construction of Normalcy

The eugenic project reached far beyond the brick and fenced walls of the concentration camps in Germany during the Second World War. Snyder and Mitchell (2006) remind us that the eugenics project was international in scale, its racist and ableist ideologies stretching far back into the 18th century and whose affects we continue to experience today. In addition to state practices that enforced eugenic ideologies, including the mass institutionalization and sterilizations of those deemed ‘unhealthy’ and ‘feebleminded’ and the eradication of hundreds of thousands of disabled people, the eugenics project was also a cultural project that constituted the characteristics, measurements, and even possibilities of a healthy, active, and productive human body. This normal body, supported by pseudo-science and a complex system whose goals were carried out by its advocates (Davis, 2006), influenced the construction and manufacturing of everyday objects and materials. The effort to eradicate difference throughout many Western societies in these first decades of the 20th century meant that many cultural objects were embedded with normative and hence eugenic ideologies (Cogdell, 2004).

In relation to children, Smith (2004) argues that eugenics entered the home and the early days of a child’s life through the capturing and categorizing of baby pictures and the ‘family album.’ Sir Francis Galton (as cited in Smith, 2004), the man who coined the term ‘eugenics,’ developed two family albums for parents to document everything about the family, including a specific section on the ‘ailments and illnesses’ of the family. Smith (2004) writes that Galton considered the “rise and fall of families [to be intricately tied and statistically important to] the rise and fall of the races” (Smith, 2004, p. 363). While eugenics may have entered the home through the organization and classification of the family album, it stayed current and influential by infiltrating the child’s toy chest. Ott (2014) describes how toys and baby books are, “powerful eugenic records that reinforce an aspiration to ‘normalcy’ and provide parents with ways of monitoring their children’s development and physical capabilities” (p. 132). The toy specifically, she argues, “can be read as reinforcing cultural beliefs about the undesirability of diversity in bodily difference” (Ott, 2014, p. 132). We can, therefore, classify the toy, any toy, as a disability material culture object. These toys are rooted in eugenic ideology: eliminate ‘defectiveness’ and ensure control over the evolutionary process.

The Toy Gymnast

The following is a disability material culture analysis of the Toy Gymnast. We recast this object as a cultural agent of various interlocking and hegemonic discourses, and in particular, explore how normative discourses are reflected in material objects. We suggest that the Toy Gymnast represents and reinforces these discourses and is therefore, one influence on

how children learn that normative bodies are desirable. We trace the toy's origins and its connection to national and international stages, the circus, the freak show, and the Olympics to demonstrate how commonplace and everyday objects are imbued with normative and eugenic discourses. Finally, and without negating the problematic discourses represented in the toy, we consider how it might also have helped children cope with their new circumstances in the hospital while teaching them about their capacity to act upon and shape the world in ways that could benefit them.

Object's origins

To start accumulating some of this toy's history, we began by searching for academic articles or other academic texts that describe the history of the toy; no such source was found. We then searched for other texts that describe the history of the toy; again, to our knowledge, no such document existed. However, in our online search for secondary sources we discovered two patents for toys similar to the Toy Gymnast. Moreover, we consulted with other sources of information and found further connections to the toy at The Strong National Museum of Play (Hogan, 2011). The curator's interpretations at The Strong and the two patents we discovered help to tell a speculative history of the toy.

Figure 2. Crandall's The Acrobats, circa 1867. Courtesy of The Strong, Rochester, New York (Hogan, 2011).



Image Description: Four small wooden figurines stacked on top of each other, three figures on the bottom row and one on the top row, much like a cheerleading pyramid. Beside the pyramid of figurines is a wood box where they are stored with the text, "Crandell's Building Blocks. Crandell's Great Show, THE ACROBATS. Full of Fun and Frolic, and Most Brilliant in Costume. Will exhibit at the house of the purchaser Afternoon and Evening. NO POSTPONEMENT ON ACCOUNT OF WEATHER MATINEE EVERY MORNING.

Admission Free, Children Half-Price.”

Hogan (2011) provides us with a starting point to understand the fascination with acrobatic and gymnastic toys. She suggests that these toys originated as products meant to represent circus acts and trapeze performers. She argues that Charles M. Cardnall, the inventor of “The Acrobats” (Figure 2), was inspired by the circus acts that were an extremely popular form of entertainment in North America and Europe throughout the later part of the 18th and early 19th centuries (Hogan, 2011). ‘The Acrobats’ are miniature wooden figurines meant to stack on top of each other much like a cheerleading pyramid. While this object has no physical resemblance to the Toy Gymnast, it does represent both acrobatic and gymnastic talent, which is evocative of the object under study. More importantly, ‘The Acrobats’ provide a reasonable explanation for the fascination and popularity of these toys, the circus.

The first incarnation of Jacob Schwennesen’s toy invention – a toy similar to the one Lynn was gifted – was invented in 1872 (see Figure 3). The figure in this invention was connected to two wooden sticks by a short, loose string, which was threaded between the figure’s hands. Opposite from the figure, the player would squeeze the ends of the sticks, and the figure would then spin around the string in whimsical and silly ways. This toy, much like Cardnall’s ‘The Acrobat,’ was meant to portray the capabilities of a gymnast.

Figure 3. The Patent Drawings for Jacob Schwennesen’s Toy Invention, circa 1872 (Schwennesen, 1872).

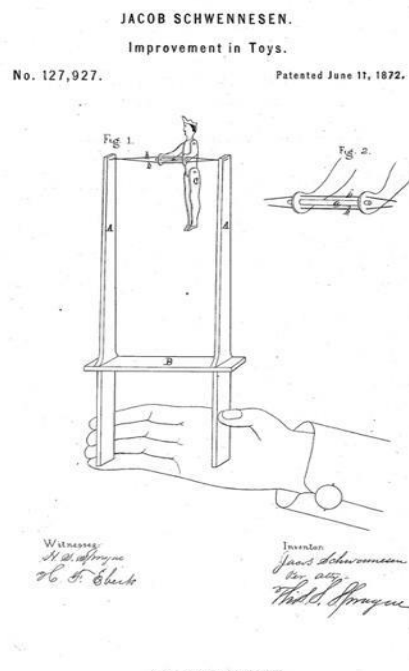


Image Description: A patent drawing of a small figure attached by a string to two wooden sticks, which when squeezed force the figure to spin around on the string. The drawing includes the text, “JACOB SCHWENNESEN. Improvement in Toys. No. 127, 927. Patented

June 11, 1872. Witness [signature of two witnesses] and Inventor [signature of three inventors].”

Mechanical versions of the toy were not far behind. In fact, the patent for H. L. Brower’s first automatic toy was in 1873—just one year after Schwennesen’s original patent.

Figure 4. The Patent Drawings for Henry. L. Brower’s Invention, circa 1873 (Brower, 1873).

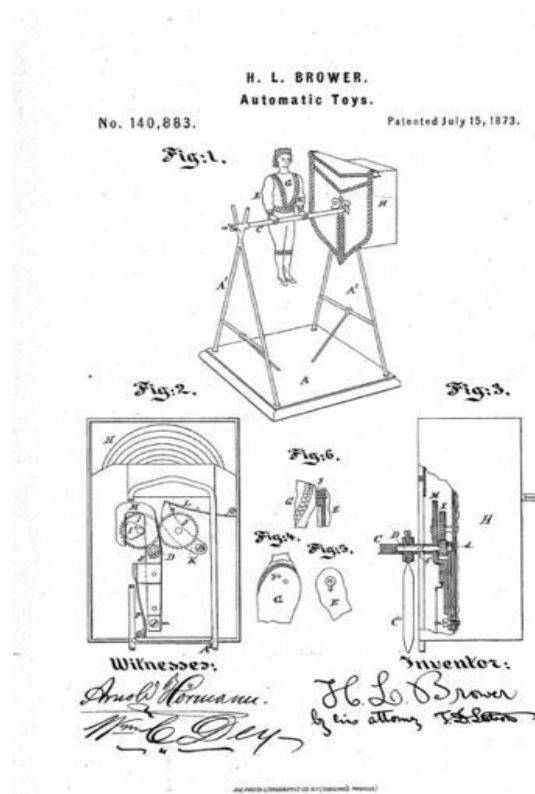


Image Description: A patent drawing of a small figure attached by a string to two wooden sticks, which when squeezed force the figure to spin around on the string. The drawing includes the text, “H. L. Brower. Automatic Toys. No. 140,883. Patented July 15, 1873. Witness [signature of two witnesses] and Inventor [signature of two inventors]”. This version includes a more stable base, and a widening mechanism.

Brower (1873), the inventor, describes the toy:

I make [sic] a toy image of an athlete with a bar capable of being revolved and oscillated and combine therewith clock-work and peculiar gearing which gives the bar such motions as [sic] induces a variety of fantastic movements. The figure if formed with a catch at the junction of one or both the arms with the body, to prevent an unnatural backward movement. The figure actuated by the mechanism performs partial or complete revolutions alternately in opposite directions around the bar under conditions which cause the movements to vary irregularly at nearly or quite every oscillation (p. 1).

In addition to explaining how the toy works, what is especially fascinating about Brower's (1873) explanation is that he notes how the new mechanism now produces a more realistic representation of human movement. The toy figure no longer moves in fantastical ways; 'unnatural backward movement' has been eliminated. One must wonder why a toy would require such restrictions. It suggests that the toy is more than a plaything, rather, that meaning and knowledge are being conveyed and communicated between the player and the toy.

In addition to limiting the toy's movements to represent more humanist features, the toy's physical appearance also shifted during this time to closely resemble a human boy/man. We credit this shift to the changes in manufacturing material. With the introduction of plastics and specifically celluloid (between 1870–1920) we found that figures became more human like and representative of ideal human forms (Figure 5).

Figure 5. Antique USSR Child Mechanic Celluloid Toy Gymnast, circa 1950s. Courtesy of Global Antiques (n.d.).



Image Description: Between two thin steel A-shaped frames – with another thin steel bar between them (resembling a swing set) hangs a white, plastic, male figure. A small mechanical winder is attached to the bottom of one of the A-shaped frames. When wound, the figure spins around the bar like a gymnast.

In Figure 5, the body is now more refined, with slightly bent arms at the elbow, more refined legs showing kneecaps and calf muscles; the face is given depth with sculpted cheeks and nose. The body depicted here is a well-formed, strong, white, male, gymnast. Although there are slight variations between Lynn's Toy Gymnast and the toy in Figure 5, they are still

very similar in style and composition. However, Lynn's Toy Gymnast was mostly likely manufactured in Japan during its occupation by the U.S. in the 1940s (1945–52). The toy in Figure 5 was manufactured in Russia during the 1950s. After the 1930s we found that many figures had the same or similar features and that they all began to represent a single ideal body type: male, white, strong, and symmetrical. The toys all had perfectly shaped or sculpted arms; smaller higher waists; larger, further apart open eyes; and, proportional long legs. We found this to be an international phenomenon with objects discovered from around the world all having the same or similar features.

There are versions of the Toy Gymnast still sold today. At the time of publication, Hasbro has a version of the toy called, 'Fantastic Gymnastics Game.' This version allows the player to mechanically swing the figure back and forth on a bar and then release the figure in an attempt to 'stick a landing' on a velcro mat. This toy more accurately depicts the movements of modern or contemporary gymnasts in popular arenas, like the Olympics.

Playing with Normalcy

Any examination of the Toy Gymnast must start with the circus. In addition to being a major source of entertainment in the late 18th and 19th centuries, the circus also embodied all the curiosity and potential of human capacity that marked this time in history (Assael, 2005). Much of this curiosity was about the body itself, its potential strength and flexibility and its limitations or exceptionalities. Visitors to a circus would explore the human strength and agility of gymnasts, acrobats and contortionists and at the same time wonder, gawk, and stare at the fat, disabled, hairy, tall, and deformed bodies of the freak show. Freak shows were, after all, a major part of many famous circuses, such as those developed by P.T. Barnum (Garland Thomson, 1996). The circus and freak show, in sharing the same space, under the same big tent, offered opportunities for comparison and reinforcing of notions of ideal versus undesired bodily traits. The significance of the circus in relation to the freak show reinforces our thesis that the gymnast, and its representation in the toy, embodies hegemonic normative and eugenic discourses that constitute the normative body as desirable.

These normative discourses, embedded in the plaything, transform into expectations. This has both real and symbolic impact on the player and one's understanding of disability, movement, and capacity, especially when one is playing with such a toy in the hospital. Varga and Zuk (2013), argue that books, toys, and other pedagogical tools have the ability to shape a player or child's experience and understanding. The Toy Gymnast depicted an ideal human figure that symbolically perpetuated and promoted normative expectations about the body and movement (Davis, 2006). The toy, as a symbolic representation of normalcy, shaped the participants' desired body. This is reinforced given the location, the proximity of the toy to the hospital, which is often a site for practices of normalcy.

We include in these practices all of the efforts undertaken to correct bodies effected by polio: surgical procedures, the casting of limbs, fusing of ankles, the use of hot wool towels which preceded the stretching of muscles (an often-painful experience as recalled by participants), and the rubbing of cocoa butter onto paralyzed legs to promote greater

movement. Lynn and her family, like others, subjected themselves to various procedures to achieve or try to achieve normalcy:

I was walking with two braces and the crutches, but I was walking [...]. Now from that [10 years old] until I was about 18 or 19, I think probably [...] – in and out of [the hospital]. And they did umpteen surgeries there (Yoshida & Shanouda, 2015; Yoshida, Shanouda, & Ellis, 2013).

Her use of the word “umpteen” meaning “countless” or “innumerable” suggests that corrective surgeries became a commonplace and regular practice for Lynn and her family. In other parts of her interview, she recalls the many visits she made to the hospital throughout her young life. Our suggestion of the real and symbolic impact of normative discourses is especially revealing in Lynn’s case – however, this should not be considered anecdotal evidence. Of the 36 participants interviewed for our larger study, 24 of them had at least one surgery, with 11 participants describing having to undergo multiple corrective surgeries as children. Certainly, many of the surgeries were necessary; however, participants also described some of the surgeries as ‘utter failures,’ ‘experiments,’ and as ‘unwanted.’²

Moreover, the hospital, as the site where play was taking place, was not a welcoming space for bodies of difference. Lynn articulates this well. When asked if they traveled by wheelchair in the hospital, Lynn reveals the extent to which walking was not simply the most desired outcome, but the expected one:

No, no. No wheelchairs. I was never, ever put in a wheelchair. They didn’t even have such things, in the hospital. Maybe they did for transporting. But see you were expected to walk. If you didn’t walk, you were in bed. And that was it. [...] And I remember getting up on my braces the first time and standing on crutches being pretty proud of myself. And my Mom and Dad just almost in tears seeing me there. But that’s what it was. I mean you either walked or you didn’t do anything, you were in bed. But there was NEVER a thought of anybody using a wheelchair. At least when I was there; now that was the way we were (Yoshida & Shanouda, 2015; Yoshida, Shanouda, & Ellis, 2013).

By removing wheelchairs and enforcing the desire to return to a supposed normative state, to walk again, hospitals ensured that bodies out of bounds would strive to reclaim their normalcy. This expectation was part of an emerging rehabilitation philosophy shaped by the aftermath of the Second World War (Anderson, 2011). Medical ideology of bringing back individuals to complete and healthy bodies was in many ways mirrored in the effort throughout Western countries to rebuild the nation state. Therefore, the disabled body, the body out of bounds, needed to be brought back in line with the image of the nation state as a healthy body (Garland Thomson, 1997; Lacom, 2002).

Nation building, according to Davis (2006) refers to a process of constructing a strong and powerful national image by perpetuating the dominance of the normal in everyday civilian lifestyles, including reinforcing normative body types and movement. The toy

contributed to this dominance of normalcy by being a representation of what the body should look and act like, much like the gymnast in the circus (Davis, 2006). In fact, as Assael (2005) argues, the circus was a site of ‘consolidated patriotism’ where the theater of war was on display and patriotic representations were available for mass consumption. Thus, the toy body can be seen as a metaphor for the robustness and capacity of the national body. If one did not fit this image, or if one’s body was different from this form, (e.g. disabled, disfigured, other) then they were thought not to be able to contribute to society and were also seen as a potential burden on the nation (Davis, 2006).

The importance of a normative body to nation-building is also reflected in the Olympic movement. After all, the Toy Gymnast depicts an athlete and its continued popularity, even the existence of the toy, after both the circus and freak show lost their appeal in the late 19th century can be tied to the success of the sport at the largest athletic tournament in the world, the Olympics. Of course, the Olympics have always represented a normative ideal, but not more so than in 1936 when it was held in Berlin, Germany, just before the start of the Second World War. McFee and Tomlinson’s (1999) analysis of Leni Riefenstahl’s film *Olympia* of the 1936 Berlin Olympic Games and selected aspects of Riefenstahl’s film *Triumph of the Will* of the 1934 Nazi Party Nuremberg Congress—demonstrate how Riefenstahl’s emphasis on a visual celebration of the human body—using classical Greek antiquity—provides a representation of innocence. In addition, it diverts attention away from the racist and ableist values, and ideologies that are reproduced in the film. Specifically, the film in its opening scenes depicts a Greek landscape, with statues of antiquity that transform before our eyes into ‘live Aryan bodies,’ white, naked, strong, muscular, symmetrical and athletic. These figures throw the discus and the javelin, and we see the torch relay move through different regions in Europe before it reaches Berlin. According to McFee and Tomlinson (1999), the torch relay serves to link Berlin (and we suggest, by extension, the Nazi regime) with that classical past. While there is no accompanying commentary, the film speaks volumes about the type of body that is to be celebrated. We cannot ignore the fact that at the same time the Olympics were taking place, thousands of disabled people were being rounded up in Germany to be institutionalized and sterilized. An estimated 300,000 – 400,000 disabled people were sterilized before and during the Second World War, including individuals diagnosed with feeble-mindedness, schizophrenia, and epilepsy (Snyder & Mitchell, 2006; United States Holocaust, n.d.). This does not include the hundreds of thousands of disabled people who were murdered by the Nazis during the Second World War.

The Berlin Olympic Games also hosted a shattering moment for the ‘science’ that constituted whites as racially superior – Jesse Owens’ four Olympic gold medals. This was a significant moment in history that reflected negatively on the Nazi Regime which had spent so much time and money ensuring a victory for their athletes. Still, Jesse Owens’ victory at the Olympics was not reflected in American material culture, especially in the figures and images that represented athleticism. For decades after Owens’ wins, children’s toys continued to depict prominent individuals as singularly white. Negative depictions of black people in children’s literature and the racist embodiment of black people in the Golliwog would

continue for decades. Wilkie (2000) provides some clarification on this matter, suggesting that “toys not only mirrored societal ideals that emphasized Aryan features (blond, blue-eyed, fair-skinned), but also reflected racial stereotypes” (p. 105). The Toy Gymnast, as we described before was always depicted as white, even when manufacturing of the toy was not in Western countries. By ensuring that these pedagogical tools also reflected ideal physical features, the toy reproduced normative portrayals of whiteness and ensured the representations of white supremacy persisted. Although it may seem like an overstatement to constitute such authority onto a toy, any attempt to extricate the toy from the racial discourses it represents is problematic. Varga and Zuk (2013) make this especially clear when they argue that to “...disentangle the discourse of white childhood racist representation... [without acknowledging this action as,] ...an assertion of racial power [is] to reinstate a hierarchical order of human values that serves white interests” (p. 665). In the banality of playing with the Toy Gymnast, racist discourses are reproduced and racial hierarchies, which were equally inscribed onto society through the eugenic project, are reflected.

Others may suggest that a young woman playing with a figure so overtly masculine may be a moment of subversion. Young women did of course play with dolls and other traditionally female playthings in the hospital. Lynn is a primary example of this as she played with both dolls and the Toy Gymnast. However, to understand how heteronormative discourses might play out in this particular moment it is essential to consider Lynn’s gender in relation to her disability. Lynn’s femaleness might have prevented closer inspection or surveillance of the items she was playing with, and as such, she may have been able to play with toys traditionally for both male and female players. In fact, as Grant (2004) argues, it was young men’s interactions with playthings during this time that was of particular concern for medical authorities. Grant (2004) argues that boys who played with dolls or other traditionally female items, could become subject to medical or clinical intervention; to prevent them from becoming ‘sissies.’ Additionally, disabled bodies, including Lynn’s at the time, have a long history of being denied sexual experiences (Shakespeare, Gillespie-Sells, & Dominic, 1996). These dominant assumptions persist about disabled people’s inability to participate in sexual experiences (Kauffman, Silverberg, & Odette, 2003). Lynn, at the time of acquiring her disability would have been thought of as ‘damaged goods’ (Phillips, 1990), and therefore, both marriage and children would have been unthinkable and often times cautioned against. The same heteronormative expectations that exist for the rest of society do not always come into play for disabled people. Here, disability offers scholars an interesting limitation to heteronormative discourses; what happens when sexuality is considered not only inappropriate and dangerous, but also impossible?

The male representation of the Toy Gymnast, however, is still an important consideration in this analysis as it helps illustrate how normative and gendered discourses interlock. Thomas (2003) suggests that Barbies and other traditionally female playthings were culturally associated with gendered ideals of passivity, nurturing, and submission. These are not traits or characteristics commonly associated with the promotion of normalcy. In fact, a Disability Studies perspective draws us to consider how the Toy Gymnast, in enacting

heteronormative male ideals—such as stoicism, perseverance, and self-reliance—was a purposeful gift that sought to instill in the player a drive to walk again, heal, and be active. After all, what was being asked of these children was not for them to care or nurture their bodies. Rather, quite the opposite. Like an athlete or a soldier, they were being asked to contort, manipulate, and essentially push their bodies to the edge. The Toy Gymnast was meant to inspire such movement and passion, swinging, rotating, swaying, always patterned, in flow, and in keeping with the pace. Furthermore, playing with dolls, which young women did in the hospital might have been a way for them to practice traditional female traits such as care, and express the affection and support they may have desired from family and medical staff who were pushing them so hard.

Learning agentic capacity

To continue this line of thought and as a way to avoid, what Baxter calls, “the imperial practices of adults”, that is the possibility of only discussing the object as it is reflected from the perspective of older individuals, we want to consider the possibility of the toy as an element that helped children cope with their changing circumstances (as cited in Brookshaw, 2009, p. 380). Moshenska (2008) describes how children’s collections of shrapnel during the Second World War, for both play and trading may also be read as a means of coping with the ravages of the War. Collecting and then playing with these once violent objects, Moshenska (2008) argues that this might have been a way for children to mitigate their experiences of war. We could argue that much like the children in war-torn Britain, but not analogous to those experiences of war, children affected by polio also relied on the material objects around them to make sense of and cope with the new conditions of their bodies. Although not shrapnel, toys and things they received from parents, siblings, and family members meant a considerable amount during this transition when many were forcibly confined to beds or iron lungs. The Toy Gymnast, powerful, muscular, mobile, the antithesis to the majority of the children’s experiences of their bodies at the time, in addition to promoting a particular discourse of normalcy may also be read as a tool that helped mitigate polio-children’s new circumstances. After all, the Toy Gymnast, mobile as he may be, also required the act of a child to move him. His actions and representation, although clearly hyper-normative, were also dependent on others and not without limitations. Moshenska (2008) theorizes that the collecting, ordering, and trading of shrapnel was about children’s attempts to regain a sense of power, specifically in relation to controlling the material that was causing the fear and death around them. Unlike shrapnel, the materials of disease, and specifically of polio, were out of reach for most children. Wheelchairs, stethoscopes, leg braces, cribs/beds, iron lungs as well as the hospital rules were not easy for children to manipulate, although they tried. One participant described spitting games from the confines of her crib and tossing balls back and forth and making staff retrieve them when they were dropped. Children in iron lungs, who only had the capability of using their mouths or face to manipulate the world around them, often used mirrors attached to the iron lung to communicate with each other and to play. Although they were confined, children did find ways to act upon and control the space around them, even in small ways, like in their ability to wind-up the mechanism that allowed the Toy Gymnast to sway. We suggest that in having this capacity to act upon the world around them,

children learned about their agentic capabilities. The agency they learned, through playing with toys and other objects in the hospital, would prove to be beneficial as they grew up and had to actively navigate an inaccessible and often discriminatory society. The Toy Gymnast therefore was a site of learning both about how their bodies were different and could be classified as broken and non-normative (and in need of repair), but also how they could reject those discourses (however difficult) and act upon the material elements around them to change them to fit their needs. We return to Lynn, one final time for an example of how this worked. As Lynn expressed earlier, using a wheelchair was not an option in the hospital and for most of her life she adopted similar normative discourses, of perseverance and independence by opting not to use a wheelchair. However, Lynn did eventually decide to use a wheelchair in her place of employment. Her decision allowed her to continue to work and she negotiated its use in the workplace. Lynn does not attribute her use of the wheelchair later in life to playing with a Toy Gymnast as a child, nor are we arguing that this is the case. Rather, we are contending that as powerful and omnipresent as heteronormative discourses are in society and in the material things around us, especially around children, disabled people did push back against those discourses and practiced an agentic force that allowed them to advocate for access to work, love, life...and play.

Conclusion

We present in this paper a demonstration of the potential a Disability Studies perspective offers to material culture analyses. Although disability was an immanent part of the contextual history of this object, we have demonstrated the breadth and depth that a disability material culture analysis can provide to scholars. In addition to considering the gendered, racialized, and heteronormative features that are represented in the Toy Gymnast, and the spaces within which children were playing with it, we must also consider what messaging is being communicated to children about bodies of difference. The messaging that reinforces bodies of difference as inferior, incapable, or that more subtly encourages normative and unattainable representations of the body need to be rejected and critiqued.

We cannot ignore the fact that this Toy Gymnast, for long parts in its history was made from celluloid, a highly flammable and combustible material that was later banned from use precisely because of its dangerous properties. We contend that there may be no better metaphor for the illusion of normalcy than to be compared to such a hazardous and precarious material. Normalcy is ultimately a harmful concept that does little else but create division in society and isolates those who fail to meet its unattainable standards. For those of us who are different, other or disabled, normal has always been an illusion, a mirage of significant proportions, with a devastating and deadly history. We have read this history onto the Toy Gymnast, a seemingly innocent plaything given to a child as a means to keep them company during their stay in the hospital. However, as we have demonstrated, the toy was also a cultural agent imbued with various hegemonic discourses that have, for those who played with it, both symbolic and real impact.

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This research was supported by the Social Sciences and Humanities Research Council of Canada [grant number 410–2009-2272], awarded to Karen K. Yoshida as Principal Investigator." If no, can you add this sentence to end the first endnote? The first endnote will, therefore, look like this: "This paper is part of a larger academic–community research project that focuses on documenting the oral life histories of Canadians who contracted polio prior to 1955 (see Yoshida & Shanouda, 2015; Yoshida, Shanouda & Ellis, 2013). This research was supported by the Social Sciences and Humanities Research Council of Canada [grant number 410–2009-2272], awarded to Karen K. Yoshida as Principal Investigator.

References

- Anderson, J. (2011). *War, disability and rehabilitation in Britain: 'Soul of a nation'*. Manchester: Manchester University Press.
- Ask Ottawa, British aid to fight prairie polio. (1953, August 15), *The Globe and Mail*.
- Assael, B. (2005). *The circus and Victorian society*. Charlottesville: University of Virginia Press.
- Brower, H. L. (1873). *Automatic Toys. Patent No. 140883*. Retrieved March 15, 2017, from <https://patentimages.storage.googleapis.com/pdfs/d31913648c68478fe9f2/US140883.pdf>
- Brookshaw, S. (2009). The material culture of children and childhood: Understanding childhood objects in the museum context. *Journal of Material Culture*, 14(3), 365–383.
- Brown, B. (2001). Thing theory. *Critical Inquiry*, 1(28), 1–22.
- Cogdell, C. (2004). *Eugenic design: Streamlining American in the 1930s*. Philadelphia: University of Pennsylvania Press.
- Davis, L. (2006). Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L. Davis (Ed.), *Disability studies reader: Second edition* (pp. 3–16). New York and London: Routledge.

- Deetz, J. (1996). *In small things forgotten: An archeology of early American life*. Toronto and New York: Anchor Books, Random House.
- Fraze, C., Church, K., and Panitch, M. (2016). Fixing: The claiming and reclaiming of disability history. In C. Kelly & M. Orsini (Eds.), *Mobilizing metaphor: Art, culture, and disability activism in Canada* (pp. 25–52). Vancouver and Toronto: UBC Press.
- Garland Thomson, R. (1996). Introduction: From wonder to error – A genealogy of freak discourse in modernity. In R. Garland Thomson (Eds.), *Freakery: Cultural spectacles of the extraordinary body* (pp.1–22). New York: New York University Press.
- Garland Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Global Antiques, (n.d). Retrieved March 15, 2015, <http://www.ebay.com/usr/globalantiques>
- Grant, J. (2004). A “real boy” and not a sissy: Gender, childhood, and masculinity, 1890–1940. *Journal of Social History*, 37(4), 829–850.
- halifax, n. v. d. (2014). Reading boots: Reading difference. *Radical Psychology*, 8(1), 1–15.
- Hogan, P. (2011). Charles M. Crandell toys—Vintage playthings, modern play [Blog post]. Retrieved April 20, 2015, from <http://www.museumofplay.org/blog/play-stuff/2011/03/charles-m-crandall-toys>
- Kauffman, M., Silverberg, C., & Odette, D. (2003). *Ultimate guide to sex and disability : For all of us who live with disabilities, chronic pain and illness*. San Francisco: Cleis Press Inc.
- Lacom, C. (2002). Revising the subject: Disability as “third dimension” in “Clear Light of Day and You Have Come Back”. *NWSA Journal*, 14(3), 138–154.
- McFee, G., & Tomlinson, A. (1999). Riefenstahl’s Olympia: Ideology and aesthetics in the shaping of the Aryan athletic body. *The International Journal of the History of Sport*, 16(2), 86–106.
- McVeigh, B. (1996). Commodifying affection, authority and gender in the everyday objects of Japan. *Journal of Material Culture*, 1(3), 291–312.
- Moshenska, G. (2008). A hard rain: Children’s shrapnel collections in the Second World War. *Journal of Material Culture*, 13(1), 107–125.
- Narduzzi, D. (2013). Regulating Affect and Reproducing Norms: Alice Munro's " Child's Play". *Journal of Literary & Cultural Disability Studies*, 7(1), 71-88.
- Ott, K. (2002). The sum of its parts: An introduction to modern histories of prosthetics. In K. Ott, D. Serlin, & S. Mihm (Eds.), *Artificial parts, practical lives: Modern histories of prosthetics* (pp.1-44). New York: New York University Press.
- Ott, K. (2014). Disability things: Material culture and American disability history, 1700–2010. In S. Bruch, & M. Rembis (Eds.), *Disability histories* (pp. 119–135). Urbana, Chicago, and Springfield: University of Illinois Press.

- Parrott, F. R. (2005). 'It's not forever': The material culture of hope. *Journal of Material Culture*, 10(3), 245–262.
- Phillips, M. J. (1990). Damaged goods: Oral narratives of the experience of disability in American culture. *Social Science and Medicine*, 30(8), 849–857.
- Schwennesen, J. (1872). *Improvement in Toys. Patent No. 127927*. Retrieved March 15, 2017, from <https://docs.google.com/viewer?url=patentimages.storage.googleapis.com/pdfs/US127927.pdf>
- Shakespeare, T., Gillespie-Sells, K., & Dominic, D. (1996). *Sexual politics of Disability: Untold desires*. London & New York: Cassell.
- Smith, S. M. (2004). Baby picture is always perfect: Eugenics and the reproduction of whiteness in the family photograph album. In V. R. Schwartz, & J. M. Przyblyski (Eds.), *The Nineteenth-century visual culture reader* (pp. 358–370). New York: Routledge.
- Snyder, S. L., & Mitchell, D. T. (2006). *Cultural locations of disability*. Chicago: University of Chicago Press.
- Thomas, J. B. (2003). *Naked Barbies, warrior Joes, and other forms of visible gender*. Urbana & Chicago: University of Illinois Press.
- United States Holocaust Memorial Museum. (n.d.). Mentally and Physically Handicapped: Victims of the Nazi Era. Retrieved March 18, 2017, from <https://www.ushmm.org/m/pdfs/2000926-Handicapped.pdf>
- Varga, D., & Zuk, R. (2013). Golliwogs and teddy bears: Embodied racism in children's popular culture. *The Journal of Popular Culture*, 46(3), 647–671.
- Whatever Happened to Polio?*. (n.d.). *Smithsonian National Museum of American History*. Retrieved March 19, 2017, from <http://amhistory.si.edu/polio>
- Wilkie, L. (2000). Chapter 8: Not merely child's play: Creating a historical archeology of children and childhood. In J. S. Derevenski (Ed.), *Children and Material Culture* (pp. 100–114). London & New York: Routledge.
- Yenika-Agbaw, V. (2011). Reading disability in children's literature: Hans Christian Andersen's tales. *Journal of Literary & Cultural Disability Studies*, 5(1), 91–108.
- Yoshida, K. K. and Shanouda, F. (2015) A culture of silence: Modes of objectification and the silencing of disabled bodies. *Disability & Society*, 30(3), 432–444.
- Yoshida, K. K., Shanouda, F. and Ellis, J. (2013). An education and negotiation of difference: The 'schooling' experiences of English-speaking Canadian children growing up with polio during the 1940s–1950s. *Disability & Society*, 29(3), 345–358.

Endnotes

1. This paper is part of a larger academic–community research project that focuses on documenting the oral life histories of Canadians who contracted polio prior to 1955 (see

Yoshida & Shanouda, 2015; Yoshida, Shanouda & Ellis, 2013).

2. Our research discovered other treatments used to combat polio including serums, nasal sprays marketed as preventative measures, and even the *Globe and Mail* (1953) reported on a San Francisco treatment that used non-poisonous snake venom.



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Research Article

‘With Hope to Help Ourselves and Others’: The Impact of Disabled People’s Organisations on the Lives of Persons with Disability in Uttarakhand, North India

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Abstract: This study conducted in Uttarakhand, North India aims to contribute evidence on the effectiveness of Disabled People’s Organisations in a low and middle-income context. Key domains reported by participants included: increased social connectedness, personal development, livelihood, improved sense of community, and participation within the family.

Keywords: Disabled People’s Organisations; Persons with Disabilities; Inclusion

Background

Disability is a complex and evolving concept. The conceptualization of disability outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is perhaps the most salient and representative of persons with disabilities. It defines persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, Art. 1).

The barriers mentioned in the Article 1 of the Convention on the Rights of Persons with Disabilities (CRPD) may include limited awareness of disability or negative attitudes within communities; inaccessible buildings or transport; lack of access to information in accessible formats; or policies that do not promote equal participation by persons with disabilities (United Nations, 2006).

Stemming from the disability rights movement in the 1970s, the rights-based approach to disability emphasizes the dignity of persons with disability and their right to enjoy life on an equal basis with others (GIZ GmbH & CBM, 2012). The rights-based approach to disability inclusion recognizes that persons with disabilities have the same rights as persons without disabilities within society, such as the right to basic health care, thus embodying a paradigm shift away from the previous social welfare response to disability (Kayess & French, 2008). Moreover, this approach supports the implementation of the CRPD as it empowers people to know about their rights and increases the capacity and accountability of individuals and institutions to address barriers to attaining these rights (GIZ GmbH & CBM,

2012). ‘Nothing about us without us,’ a negotiating slogan adopted by the International Disability Caucus, is the principle in which the CRPD represents continual partnering between the United Nations (UN) and persons with disabilities (Kayess & French, 2008). Disability-inclusive practices envisions that persons with disabilities can fully participate in all aspects of society and have the potential to significantly contribute to their families and communities (CBM Australia, 2012).

Disabled People’s Organisations are established by and for people with disabilities. At the board and membership levels, DPOs are controlled by a majority of persons with a disability (at least 51%) (PWDA, 2017). The role of DPOs is to provide persons with disabilities with a voice of their own, identify needs, express views on priorities, evaluate services and advocate change and public awareness (PWDA, 2017). As a key pillar in the response to global disability, DPOs act to promote participation and wellbeing through activities such as advocacy, service provision and social support.

Community-based rehabilitation (CBR) is a strategy developed by the World Health Organization (WHO) following the 1978 Declaration of Alma-Ata. The purpose is to strengthen DPOs and provide equal opportunity and social inclusion for all persons with disabilities. This strategy promotes collaboration between persons with disabilities, community leaders, and their families to ensure inclusion and participation of persons with disabilities (WHO, 2017). Thus, CBR highlights the importance of DPOs in promoting inclusion. CBR is visually represented by the CBR Matrix (WHO, 2010) and consists of five key components, including: health, education, livelihood, social and empowerment (see Figure 1).

Figure 1 Community-Based Rehabilitation Matrix (WHO, 2010)

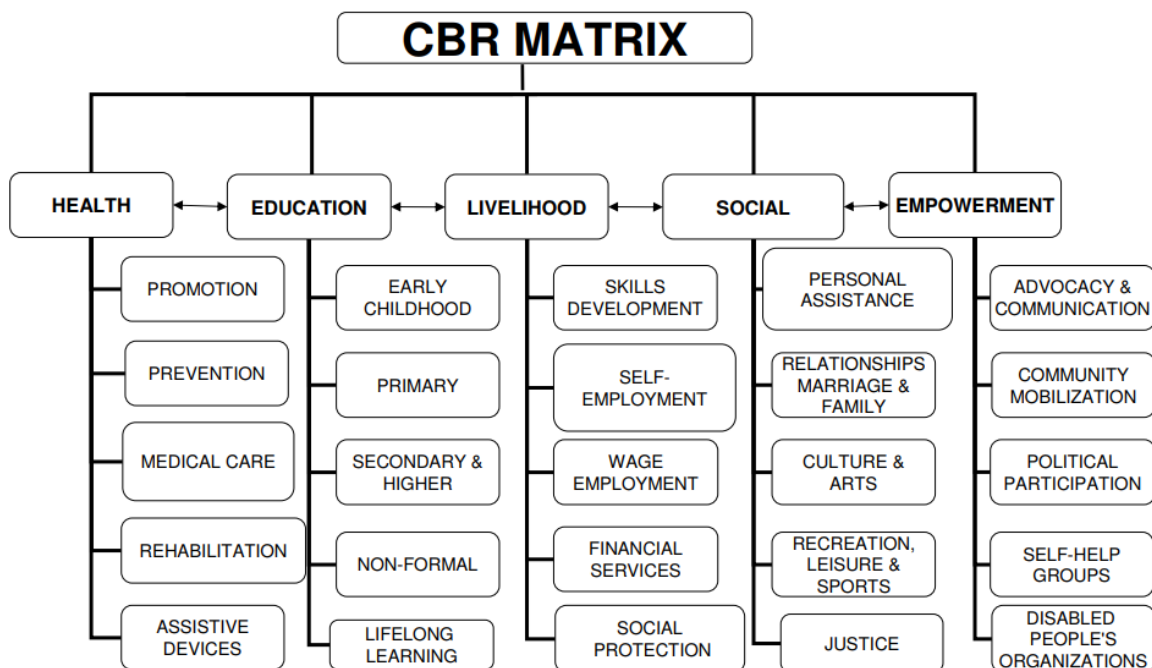


Image Description: The diagram of the ‘CBR Matrix’ includes five key components

representing health, education, livelihood, social and empowerment. Each key component includes sub-key components. The 'HEALTH' key component includes five sub-key components: promotion, prevention, medical care, rehabilitation, and assistive devices. The 'EDUCATION' key component includes five sub-key components: early childhood, primary, secondary & higher, non-formal, and lifelong learning. The 'LIVELIHOOD' key component includes five sub-key components: skills development, self-employment, wage employment, financial services, and social protection. The 'SOCIAL' key component includes five sub-key components: personal assistance, relationships marriage & family, culture & arts, recreation leisure & sports, and justice. The 'EMPOWERMENT' key component includes five sub-key components: advocacy & communication, community mobilization, political participation, self-help groups, and Disabled People's Organizations.

Since 2007, the Nossal Institute for Global Health has supported the development of a network of community health programs in North India, collectively referred to as the Community Health Global Network - Uttarakhand Cluster. The Uttarakhand Cluster has helped its members co-operate on activities such as health worker training, linking with the government health system and organizational strengthening. It has also collectively increased access to resources to improve the provision of community-level health and development services. Further, the Uttarakhand Cluster has developed a strong focus on improving the participation of persons with disabilities in their communities and promoting health and wellbeing. To support this, member organizations of the Uttarakhand Cluster have assisted persons with disabilities in forming networks and ultimately DPOs. The two DPOs studied here were formed as a result of people with disabilities coming together and realizing the need to work together. Samvedna non-governmental organization (NGO), representing the Uttarakhand Cluster, helped support the establishment of these nascent DPOs by facilitating training of the DPOs members in organizational management, their rights under the UNCRPD and advocacy options. The Samvedna NGO, henceforth referred to as the facilitating NGO, also organized learning visits to other DPOs and guided the DPOs through the complex process of applying for official DPOs registration. None of the facilitating NGO staff were members or leaders of the DPOs.

A previous process study found that the formalization of the DPOs was supported by initial efforts to promote community awareness of the rights of persons with disabilities, and financial and human resource support were provided through the Uttarakhand Cluster and local village leaders. Facilitating NGO staff worked with DPOs members to help them develop skills in effective group leadership; establishment of organizational practices and governance structures; advocacy and community awareness raising training; fundraising; and support to create more accessible environments. Local village leaders (Pradhan) provided the DPOs with a space to meet (Young, Grills, Reeve, Devine, & Singh, 2016). Networking and peer-exchanges between DPOs, whereby DPOs members of one group spent time with a more established DPOs to observe and learn from their practices. This enabled peer-led information sharing and fostered collaborative relationships between DPOs (Young et al., 2016).

Whereas the previous research has described the formation of DPOs, in this study we

aimed to contribute to the understanding of the effectiveness of DPOs in a low and middle-income context and the impact of DPOs on the lives of persons with disabilities and their families.

Methods

This qualitative study involved conducting semi-structured interviews and focus group discussions (FGD) - between February and March 2017 - across two study sites (of 15 DPOs sites) in Uttarakhand, North India. Ethics approval was received from the University of Melbourne Human Research Ethics Committee (HREC) and the local ethics committee of the Community Health Global Network (CHGN). In consultation with the facilitating NGO, the two sites selected were considered feasible for conducting the research, as well as, ensuring geographical representativeness and demographics of the study population. The first study site was located in the plains region of Dehradun District, with the second site located in the mountain region of Tehri Garhwal District (see Table 2 and 3 for demographics of the sites).

Table 2 *Demographics of the two DPO sites*

DPO study site	Location	Month/year of first group meeting	Number of DPO members at site	Age range	Location
1	Tehri Garhwal	January 2015	32	18-61	Samvedna Centre, Thatyur
2	Dehradun District	May 2015	44	18-70	Aarohi Sweet Shop, Badripur

Study Population

The study population were persons with disabilities currently participating in the DPOs, their family members and facilitating NGO staff (see Table 3 for demographics of study participants). The facilitating NGO staff were experienced in community mobilization and in working with people with disabilities.

Persons with disabilities were purposively sampled for interview in consultation with the facilitating NGO staff and DPOs members. The research team ensured a representative sample of age, gender, and type of disability, as well as, representation from people with different levels of involvement and inclusion in the DPOs activities. Family members that were recruited for interviews, were selected in consultation with persons with disabilities being interviewed. The NGO leaders helped identify the appropriate facilitating NGO staff to be interviewed. The sample consisted of twenty persons with disabilities currently participating in the DPOs, eight family members of persons with disabilities who have participated in the program, and 14 facilitating non-governmental organization staff. All participants were 18 years of age or older.

Table 3 *Demographics of Study Participants*

Type of interview	Total number of participants	Gender	Age	Type of disability
Tehri Garhwal District				
SSI (person with disability)	9	6 Male 3 Female	18–61	<ul style="list-style-type: none"> ● Physical impairment: 4 ● Sensory impairment: 2 ● Intellectual impairment: 1 ● Mixed impairment: 2
SSI (family of person with disability)	6	2 Male 4 Female	18–49	
FGD	8	4 Male 4 Female		
Dehradun District				
SSI (person with disability)	11	6 Male 5 Female	18–70	<ul style="list-style-type: none"> ● Physical impairment: 8 ● Sensory impairment: 0 ● Intellectual disability : 3 ● Multiple impairment: 0
SSI (family of person with disability)	6	2 Male 4 Female	19–53	
FGD	6	2 Male 4 Female	32–55	

Data Collection

The lead researcher conducted all semi-structured interviews and focus group discussions in English with the support of two Hindi-English translators. With the informed consent of all study participants, the semi-structured interviews and focus group discussions were recorded with an audio recording device. The duration of the semi-structured interviews

was 20 minutes, and focus group discussions was one hour. The focus group discussions and semi-structured interviews were held at DPOs meeting sites or in participants' homes when accessibility to meeting sites were difficult.

The two Hindi translators received one-day of training, which involved familiarization with the process of informed consent, semi-structured interviews and focus group discussions question guides. Question guides were iteratively developed in consultation with the staff of the facilitating NGO in India and disability researchers in Australia. Interviews were transcribed in real time and translated into English. Written or verbal consent was obtained from all study participants.

Analysis

Inductive thematic analysis was used to analyze the data. In this 'bottom up' method, the patterns observed in the data were used to generate themes (Braun & Clarke, 2006).

This technique was chosen, as this coding approach is data driven, and avoided fitting data into analytic pre-conceptions or pre-existing coding frames, thus generated some unanticipated insights. Three research team members were involved in familiarization with the transcribed data, coding (organization of the data), identification of patterns, generation of themes, and finally discussion and reconciliation of any differences. From the patterns that emerged from the data, the research team generated 6 themes that were representative of the participants' responses. Moreover, the barrier, enabler, outcome model, was utilized as an organizing framework for the analysis. This method involved sorting and grouping the recurring ideas of participants' responses (from the semi-structured interviews and focus group discussions) into the categories of barriers, enablers and outcomes within each generated theme (see Table 1).

Results

Six themes characterized the impact of the DPOs on the lives of persons with disabilities and their families (see Table 1). These themes covered the domains of 1) social connectedness, 2) personal development, 3) participation within the community and family, 4) inclusion of previously excluded groups, 5) access to services, and 6) livelihoods. Study participants described barriers and enablers related to the overarching themes as experienced by persons with disabilities and their families.

The barriers identified by the participants were a mixture of barriers related to the broader lived experience of disabilities, as well as, barriers experienced by some participants in relation to their participation in the DPOs. Some of these barriers have been reduced through participation in the DPOs, while other barriers require ongoing action to address.

Table 1 *Summary of Overarching Themes Related to the Impact of DPOs*

Theme 1	DPOs created an opportunity for socialization and connectedness
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Barriers	<ul style="list-style-type: none"> ● Negative attitudes of community towards persons with disabilities, thus leading to social isolation. ● Lack of support from community for persons with disabilities.
Enablers	<ul style="list-style-type: none"> ● Opportunity to develop friendships with other persons with disabilities and NGO staff through DPOs, thus leading to enhanced confidence that improves other relationships, such as with family. ● Mentoring of DPOs members by facilitating NGO staff. ● Social gatherings between neighboring villages.
Outcomes	<ul style="list-style-type: none"> ● Mutual understanding and peer support for individuals with disabilities, “I am not alone.” ● Peer support for family members of persons with disabilities.
Theme 2	DPOs empowered persons with disabilities
Barriers	<ul style="list-style-type: none"> ● Limited previous opportunities that promoted self-confidence and independence.
Enablers	<ul style="list-style-type: none"> ● Exposure visits to shopping malls. ● Support to develop skills that develop independence (e.g. self-care skills).
Outcomes	<ul style="list-style-type: none"> ● Increased self-confidence. ● Learning skills for increased independence. ● Increased skills for self-advocacy. ● Improved recognition of role and responsibility within the family.
Theme 3	DPOs increased involvement within the community and family
Barriers	<ul style="list-style-type: none"> ● Negative societal attitudes and stigma associated with disability. ● Lack of community support. ● Lack of family support. ● Expectation of DPOs as a service delivery.
Enablers	<ul style="list-style-type: none"> ● Attending DPOs meetings. ● Gaining knowledge at DPOs meetings.
Outcomes	<ul style="list-style-type: none"> ● Sharing knowledge with the village. ● Understanding about disability and the beneficial role of DPOs.

	<ul style="list-style-type: none"> • Greater acceptance and respect from family and community.
Theme 4	DPOs promoted inclusion of previously excluded groups into the community
Barriers	<ul style="list-style-type: none"> • Gender norms in some communities. • Communication barriers. • Attitudinal barriers. • Venue accessibility for persons with disabilities. • Geographical accessibility to villages for facilitating NGO staff.
Enablers	<ul style="list-style-type: none"> • Building relationships with family members. • Installation of ramps for wheelchair access. • Female NGO staff traveling in pairs to remote villages.
Outcomes	<ul style="list-style-type: none"> • Relationships between DPOs members and the facilitating NGO staff that is established on trust. • Inclusion of previously excluded groups such as women. • Persons with hearing impairments and intellectual disability remain excluded. • Persons with disabilities in geographically isolated settings still encounter difficulty in attending DPOs meetings.
Theme 5	DPOs increased access to government services and resources
Barriers	<ul style="list-style-type: none"> • Lack of awareness of persons with disabilities in the existence of services. • Limited access to services.
Enablers	<ul style="list-style-type: none"> • Facilitating NGO staff provided knowledge about services.
Outcomes	<ul style="list-style-type: none"> • Increased usage of disability-specific services. • Meeting material needs. • Developing relationships with health professionals.
Theme 6	DPOs contributed to livelihoods of persons with disability
Barriers	<ul style="list-style-type: none"> • DPOs meeting times interfering with work. • Lack of opportunities for persons with disabilities to work.
Enablers	<ul style="list-style-type: none"> • Income generating activities.

	<ul style="list-style-type: none"> ● Tailored meeting times to fit agricultural work schedule.
Outcomes	<ul style="list-style-type: none"> ● Increased access to income, savings, and jobs. ● Opportunity to work is not universal across DPOs sites.

Theme 1: DPOs Created an Opportunity for Socialization and Connectedness

Involvement in the DPOs provided persons with disabilities with opportunities to form social connections with other persons with disabilities and staff of the facilitating NGO. Prior to joining DPOs, persons with disabilities often experienced social isolation, and lack of support from the village and broader community. One DPOs member expressed, “[my] thinking has changed. I used to stay at home alone. There was no one like me. Now I come to the DPOs meeting, and was encouraged” (male with a physical disability, aged 30, Dehradun District).

After becoming involved in the DPOs, persons with disabilities were able to recognize that there were other persons with disabilities. Participants described the relief of discovering, often for the first time, that there were other persons with disabilities living in their communities who had shared similar circumstances and challenges. As a result, they no longer felt that they were alone and they felt a sense of connectedness with their peers. For example, one DPOs member commented, “Before joining DPO, I used to feel uncomfortable when going out. After joining DPO, I feel DPO members are my family” (female with an intellectual disability, aged 24, Dehradun District).

Facilitating NGO staff also highlighted that the DPOs increased the visibility of persons with disabilities in the community. Six out of the six NGO staff members from Dehradun district agreed that the increased visibility encouraged others to participate, “Seeing other persons with disability in DPO meetings motivates [other] persons with disability to attend” (facilitating NGO staff member, Dehradun District).

Family members also reported they found comfort and a sense of connectedness in the realization that there were other families in the community that has a family member with a disability. One father for example commented, “My son sits with other children with [a] disability. I feel good that my son isn’t the only child with disability and no longer feel sad” (father of DPOs participant with a physical disability, Tehri Garhwal).

Theme 2: DPOs Empowered Persons with Disability

Prior to joining the DPOs, participants described that their lives were negatively affected by anxiety and a lack of self-confidence. After joining the DPOs, many participants reported that they had experienced what can be described as personal growth. This included increased self-confidence, gaining independence, and improved capacity for self-advocacy. It was noted that DPOs members who were more frequently involved in DPOs activities were more likely to report on increased self-confidence and the feeling of empowerment.

Persons with disabilities and their family reported that activities organized through the DPOs, such as support to develop self-care skills and community outings, helped develop independence and fostered a sense of empowerment among persons with disabilities. As described by one family member, “She has learnt her signature and can go to the bank alone. [She] goes everywhere alone” (sister-in-law of DPO participant with a physical disability, Dehradun District). The self-confidence of persons with disabilities were also enhanced when four individuals from the Dehradun District mentioned they had positive interactions with other community members during DPOs community outings, “People in the mall respected us a lot” (female with a physical disability, aged 25, Dehradun District).

Increased self-confidence and empowerment gained through participating in the DPOs enabled participants to engage in other aspects of their communities, including the area of self-advocacy. This was most pertinently described by a participant in his newfound confidence and desire for taking ownership in advocating for persons with disabilities and leaving a legacy:

Initially, I didn’t talk to neighbors. Now I can even talk to Chief Minister of Uttarakhand. [I am] more confident...I thought, what will we as persons with disability do? Used to wait for time to pass. Now, I think we have to do something, so the world can remember us (male with a physical disability, aged 30, Dehradun District).

As highlighted by the following quote, in some cases, the confidence gained through the participation in the DPOs had a profound impact on the lives of persons with disabilities, “After joining DPOs, I have confidence, [I] can do. I started a business, got married, have daughter” (male with a physical disability, aged 25, Dehradun District).

Further, not only did the independence of persons with disabilities improve, but it also improved the families’ confidence in the capacity of their family members with a disability to be independent and participate in their communities, “Before joining DPOs, my sister did not clean herself, not dress herself. After joining DPOs, she has learnt independent care skills. In preparation for attending DPOs meetings, she dresses herself, takes bath” (sister of DPOs participant with an intellectual disability, Tehri Garhwal).

Theme 3: DPOs Increased Involvement within the Family and Community

Prior to the presence of DPOs, persons with disabilities reported there was limited understanding of disability within their communities and that they would often experience stigma and discrimination. This resulted in persons with disabilities remaining isolated within their homes. Facilitating NGO staff also highlighted that during the process of formalizing the DPOs, there was resistance from families and other community members to the idea of establishing DPOs and supporting the participation of persons with disabilities. For example:

Family members of persons with disability were unwelcoming and denied that PWD needed help. [They asked] what can you do for my family?... We had to explain that

the motive for joining DPOs is to gain rights, join community, gain resources and knowledge about government schemes (facilitating NGO staff member, Tehri Garhwal).

Participants reported that DPOs continue to promote positive attitudes towards disabilities within their communities, this includes improved understanding within the community and support from families with disability members to participate in DPOs. Additionally, the DPOs provide a platform for persons with disabilities to learn about their own rights, as well as, acquire health promotion information. DPOs participants highlighted that they are now confident to share the knowledge they have learned with their communities. This demonstration of knowledge and confidence has further shifted the mindset of the community, with family members interviewed highlighting this as a positive impact. The initial skeptical attitude adopted by the village regarding the utility of the DPOs was reversed when the village could see positive change in the lives of persons with disabilities due to their involvement in the DPOs, “Before joining DPO, villagers and family used to tease my son, and didn’t call my son by name. Now the village and my family call my son by name” (father of DPOs participant with a physical disability, Tehri Garhwal).

“Initially, [the] village was cynical about what DPO could do. But now [the village] can see change in persons with disability, [so they are] no longer cynical” (mother of DPOs participant with an intellectual disability, Dehradun District).

As a result of the village and family members developing an understanding about disability and the beneficial role of DPOs, persons with disabilities reported they were now more likely to be treated with acceptance and respect within their families and the wider community. As described by one DPOs participant, “[the] village used to make fun of PWD, they didn’t ask PWD, ‘How are you?’ [the] village now respects PWD and accepts them as equals” (female with a physical disability, aged 40, Tehri Garhwal).

Theme 4: DPOs Promoted Inclusion of Previously Excluded Groups

During the early stages of the establishment of DPOs, facilitating NGO staff reported that they encountered difficulty in including some persons with disabilities. In particular, some family and community members were resistant to the inclusion of persons with disabilities from the local Muslim communities; persons who are Deaf or hard of hearing or with other communication difficulties; and persons with an intellectual disability. Some of these families and community members acted as gatekeepers and barriers to inclusion.

In the plains region of Dehradun District, all facilitating NGO staff participating in the focus group discussion (FGD) interviews described the difficulty of engaging the Muslim community. For example, “Initially, when facilitating NGO staff approached the homes of Muslim persons with disabilities, the Muslim males rejected the female staff. After being rejected, the staff members expressed feelings of anxiety and nervousness” (facilitating NGO staff member, Dehradun District). Facilitating NGO staff described the importance of gradually building the trust with the Muslim community and family members of persons with

disabilities in order to gain their support to encourage their family members to participate in the DPOs.

Facilitating NGO staff also described ongoing efforts to develop relationships with persons with an intellectual disability and their families. While this was reported to have improved the participation of some persons with an intellectual disability within the DPOs, facilitating NGO staff acknowledged this participation is still reliant on the support of family members and/or support persons, “It is difficult to communicate with persons with intellectual disability if they are not with their caregiver or family member” (facilitating NGO staff member, Tehri Garhwal). The inclusion of persons who are Deaf or hard of hearing was reported to be prevented by the lack of the use of sign language by other people who are Deaf or hard of hearing, facilitating NGO staff, and the broader community.

All facilitating NGO staff commented that during the early stages of the DPOs formation process, physical accessibility was a major barrier to participation of persons with disabilities. Difficulty in the physical accessibility of the surrounding areas also affected both persons with disabilities traveling to DPOs meeting places, and staff of the facilitating NGO traveling to the homes of persons with disabilities. Since becoming aware of barriers in the accessibility of DPOs meeting sites, participants reported that DPOs have been collaborating with the staff of the facilitating NGO to try and improve the accessibility of meeting spaces, for example through the construction of ramps. However, persons with disabilities in geographically isolated villages still encountered difficulty in attending DPOs meetings.

Theme 5: DPOs Increased Access to Services and Resources

Before the formalization of the DPOs, persons with disabilities reportedly experienced very limited access to disability-specific and general health services. Through participation in the DPOs and the support of facilitating NGO staff, persons with disabilities and their families reported learning about government programs, such as the disability certificate which enables a person to receive a pension. Facilitating NGO staff were reported to have assisted persons with disabilities to register for these available entitlements. As such, one DPOs member remarked that, “after joining DPOs, problems were sorted, including disability certificate, pension” (male with a physical disability, aged 28, Tehri Garhwal).

DPOs members, often with the help of facilitating NGO staff, accessed other health care services including acquiring hearing aids, leg prostheses and wheelchairs. One DPOs member commented that through the DPOs, he had developed relationships with health professionals, including doctors and physiotherapists, who were then able to promote the health seeking behavior of DPOs members. Examples were also shared of DPOs members working together to mobilize help for material needs of their members, “DPO organized the repairing [of] the family house and railing. To prevent falling when she has a seizure. This convinced her to join the DPO” (sister of DPOs participant with a physical disability, Tehri Garhwal).

Theme 6: DPOs Contributed to Livelihoods of Persons with Disabilities

Some DPOs were reported to have had a focus on income generating activities for their members. For example, “We collect monthly money for savings to deposit at bank to help other members” (female with a physical disability, aged 40, Tehri Garhwal). Similarly, as highlighted by another participant, “[We have] learned candle making, organic rubbish composting, paper earrings, apron making” (female with a physical disability, aged 25, Dehradun District). For some participants, this has led to access to some income, savings and skills for acquiring a job.

However, the opportunity to work was not universal across both DPOs sites. Whereas in the mountainous region of Tehri Garhwal, many persons with disabilities were reported to be involved in agriculture work, opportunities for agricultural livelihoods or other work was reported to be limited in the plain districts of Dehradun. Participants in these areas reported they were disappointed that their participation in the DPOs had not improved access to more livelihood opportunities for persons with disabilities. One person with a disability reported for example, “DPO has given me hope to help ourselves and others, but I have not seen any changes. I would like to see changes, since disability is a barrier to work. Disability prevents work. I want to see us do our own work” (male with a physical disability, aged 42, Dehradun District).

Discussion

This study demonstrated that participation in DPOs can have a positive impact on the lives of persons with disabilities and their families. Key areas where impact was found included: social connectedness, personal development, livelihood, community, and participation within the family.

The functioning of the DPOs evaluated in this study was supported by the framework presented by the CRPD, particularly the convention’s role in detailing the rights of persons with disabilities and setting a code of implementation. We found evidence that DPOs have contributed or are contributing to Article 8 through awareness raising; Article 25 through access to health; Article 27 through work and employment; Article 30 through the participation of cultural, recreation and leisure (United Nations, 2006).

The beneficial outcomes of DPOs in this study had effects across the five pillars of the WHO CBR Matrix, particularly in advancing health, empowerment, and social inclusion (WHO, 2010, 2017). This study showed that the activities of the DPOs were beginning to address the major objectives of the CBR, including; 1) ensuring that persons with disabilities maximize their physical and mental abilities, thus becoming active contributors to the community; and 2) activating communities to promote and protect the human rights of persons with disabilities through changes within the community, for example, by removing barriers to participation. This was achieved through the combined efforts of persons with disabilities, their family and facilitating NGO staff.

Literature supporting that DPOs can improve participation of persons with disabilities in the community can be found (Young et al., 2016). In a study in India, it was similarly observed that self-help groups were an avenue for persons with disabilities to emerge from social isolation and engage in collective development and welfare (Kumaran, 2011). In addition, there were findings that DPOs challenged negative societal attitudes, resulting in greater acceptance of persons with disabilities in the village. This suggests that social connectedness of persons with disabilities with the broader community is beginning to occur.

Participating in activities conducted by facilitating NGO staff, included learning self-care skills and exposure through visits to a local mall. This enabled persons with disabilities to acquire skills and increased their self-confidence. The experience of empowerment, via participation, is consistent with other studies involving individuals with psycho-social disability in a low- and middle-income context (Carroll et al., 2016; Dhungana & Kusakabe, 2010).

Similar to what has been described in a study conducted in Nepal (Morrison et al., 2015), the DPOs in this study enabled persons with disabilities to experience greater acceptance from their family and greater engagement with their community. Participation in DPOs enabled information sharing about disabilities, which challenged and re-oriented previous negative attitudes. Moreover, there was evidence that groups of individuals, such as persons with an intellectual disability, who were previously excluded from participating in DPOs, but are now beginning to be included in the DPOs. These previously excluded groups not only included persons with an intellectual disability, but individuals from the Muslim community. Staff of the facilitating NGO reported that greater inclusion has been achieved due to DPO's addressing barriers to participation. Consistent efforts from facilitating NGO staff had reached out to previously excluded groups and their family members, which resulted in the DPOs gaining a greater understanding of the needs of these previously excluded groups. These needs included understanding the most effective way of communicating, building trust and affirming DPOs as an accessible space for all persons with disabilities (Polu & Nelson, 2015).

Our study found that DPOs enabled greater access to health and disability-specific services, consistent with the experiences of DPOs in other countries, for example Brazil (Deepak et al., 2013). During DPOs meetings, facilitating NGO staff informed DPOs members and assisted access to these services, including accessing disability pensions and mobility aids. Due to their tangible nature, access to health and disability-specific services was reported by many DPOs members as motivation for joining the DPOs. Upon participating in the DPOs, persons with disabilities then realized that service provision was not the only role of DPOs, and utilized the DPOs for activities such as advocacy and social inclusion.

The priority of income generation was a strongly voiced finding in this study. Our study showed that DPOs play a critical role in providing opportunities for persons with disabilities to improve their livelihood. By providing a supportive space, DPOs enabled persons with disabilities to engage and cooperate with peers in the common goal of

undertaking income generating activities. Opportunities for improving livelihood were not uniform across the two DPOs sites. DPOs members in the mountain region were typically engaged in agricultural work; however, several male DPOs members in the plains desired to work but felt they had no means to achieve this objective. They expressed that DPOs should be doing more to provide for this particular unmet need. Although the purpose of DPOs is to promote participation and wellbeing, it does not always translate into providing avenues for employment. A study conducted in India found that self-help groups had a vital role in facilitating persons with disabilities to work together for their collective welfare and livelihood (Morrison et al., 2015).

The barriers encountered by the DPOs in this study are acknowledged in literature. For example, in a study conducted in Bhalki, India, physical inaccessibility to venues is noted as a major barrier to attendance of persons with disabilities at DPOs meetings (Deepak et al., 2013). In our study, we found that while venue accessibility can be improved by DPOs, it is difficult to improve the accessibility to geographically isolated villages.

Lack of family and community support is commonly recognized as a significant barrier hindering persons with disabilities from participating in DPOs. As highlighted by a study in rural Nepal, we found that DPOs working alongside families to raise awareness about the benefits of DPOs attendance and participation addressed this barrier (Morrison et al., 2015).

Overall, the findings were consistent between the two DPOs sites. However, some differences existed. It was observed that the DPOs located within the plains region of Dehradun had members who were more motivated to participate in self-advocacy and in income-generating activities – some willing to take ownership of roles (e.g. President, Secretary, Treasurer) within the DPOs itself. This might be explained by the greater amount of time availability to actively engage in DPOs activities in plains populations as compared with DPOs members in the mountain region, who were often restricted by agricultural work commitments.

Difficulty in physically accessing DPOs venues may also be a contributing factor to the level of participation of persons with disabilities in DPOs activities. Moreover, education levels of DPOs members in the mountain region were generally lower than DPOs members in the plains region (see Table 3 for demographics of study participants), which may partly explain the difference in participation between the two contexts. This observation is consistent with the findings of a study in rural Nepal that described that some participants attributed their lack of education to difficulty in interacting and engaging in groups (Morrison et al., 2015).

Next Steps for DPOs, the Uttarakhand Cluster and Broader Community: Implications for Scaling-up DPOs

To improve participation of persons with disabilities in the DPOs, and ultimately enable persons with disabilities to realize their rights to participate in society on an equal basis with others, DPOs should continually address the barriers identified through this study. To

enable greater inclusion of persons who are Deaf or hard of hearing and persons with an intellectual disability. In addition, DPOs should continue activities that promote inclusion of marginalized groups of persons with disabilities in society. These activities could include facilitating NGO staff training of DPOs members in effective communication with individuals who are Deaf or hard of hearing and persons with an intellectual disability. Facilitating NGO staff members therefore need to build their own capacity to work with persons with an intellectual disability.

DPOs should increase physical accessibility of DPOs meeting venues for persons with a physical disability, particularly for individuals from geographically isolated settings. A possible strategy is to alternate DPOs meeting venues to allow all DPOs members an opportunity to meet closer to their homes. This could be arranged with the help of the local village leadership and in discussion with DPOs members and facilitating NGO staff.

To address DPOs members desiring more opportunities to improve their livelihood, DPOs should continue to work with facilitating NGO staff to better understand the barriers to livelihood opportunities for persons with disabilities in the plains districts. Subsequently, local solutions should be developed to address barriers to livelihoods. Further research could explore how DPOs can support DPOs members in opportunities for income generation.

As a result of the positive findings from this study, which showed that activities such as information sharing and exposure through visits to malls were effective ways for persons with disabilities to engage with their community, we recommend that DPOs should continue to encourage persons with disabilities to participate in self-advocacy activities.

Limitations

Ideally, if the research team would have included persons with disabilities, this may have yielded more insightful and in-depth responses. A selection bias may have occurred, as field managers helped researchers recruit participants. There may have been a tendency for the inclusion of participants who were more confident and had direct positive experiences at the DPOs. The nature of FGDs may not facilitate equal contributions from all participants.

It is difficult to know how far these findings could be generalized. Even within our study, there were differences between the two study sites. However, our findings were largely consistent with findings from other studies on the effect of DPOs. Yet given the limited published evidence on the effect of DPOs, and given their widespread use in disability and development, it is imperative that other research is done to formally assess the impact of DPOs in alternative contexts.

The findings in this study were predominantly positive about the benefits of involvement in the DPOs. However, due to the power differential from the researchers' socioeconomic, cultural and educational backgrounds, participants may have felt the need to please the interviewer and give the 'right answers'. On the other hand, common themes of areas of impact emerged and they were supported by multiple participants from different

geographical areas.

Conclusion

The study of the DPOs in Uttarakhand, North India determined that participation in DPOs had a positive impact on the lives of persons with disabilities, particularly for promoting social connectedness, personal development and livelihood. While participation in DPOs provides many benefits to persons with disabilities, many individuals still prioritize work as a core objective and an unmet need in the opportunities provided by DPOs. Many findings from this study were similarly described elsewhere in the literature, suggesting the findings might have currency when applied to other LMIC contexts. Further research may explore how DPOs can continue to better include individuals with hearing impairments and intellectual disability.

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Declaration of interest statement

The authors report no conflicts of interest.

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References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 93.
- Carroll, A., Davar, B., Eaton, J., Catherine, R., Cambri, J., Devine, A., & Vaughan, C. (2016). Promoting the rights of people with psychosocial disability in development research and programming. *Development Bulletin*, 77, 25–30
- Christoffel-Blindenmission (CBM) Australia. (2012). Inclusion made easy: A quick program guide to disability in development. Retrieved from http://www.cbm.org/article/downloads/78851/CBM_Inclusion_Made_Easy_complete_guide.pdf
- Deepak, S., dos Santos, L. R., Griffo, G., de Santana, D. B., Kumar, J., & Bapu, S. (2013). Organisations of persons with disabilities and community-based rehabilitation, *Asia Pacific Disability Rehabilitation Journal*, 24(3), 5–20.
- Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ GmbH) and Christoffel-Blindenmission (CBM). (2012). A human rights-based approach to disability in development. Retrieved from http://www.cbm.org/article/downloads/54741/A_human_rights-based_approach_to_disability_in_development.pdf
- Dhungana, B. M., & Kusakabe, K. (2010). The role of self-help groups in empowering disabled women: A case study in Kathmandu Valley, Nepal, *Development in Practice*, 20(7), 855–865.
- Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, 8(1), 1–34.
- Kumaran, K. P. (2011). Role of self-help groups in promoting inclusion and rights of persons with disabilities. *Asia Pacific Disability Rehabilitation Journal*, 22(2), 105–113.
- Morrison, J., Colbourn, T., Budhathoki, B., Sen, A., Adhikari, D., Bamjan, J., & Groce, N. (2015). Disabled women's attendance at community women's groups in rural Nepal. *Health Promotion International*, 29(11), 1–11.
- People with Disability Australia (PWDA). (2017). Disabled People's Organisations (DPOs). Retrieved from <http://www.pwd.org.au/student-section/disabled-people-s-organisations-dpos.html>.
- Polu, W. A. M., & Nelson, C. (2015). Social and economic inclusion of people with disabilities: Practical lessons from Bangladesh, *Development in Practice*, 25(8), 1182–1188.
- United Nations. (2006). Convention on the rights of persons with disabilities. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- World Health Organization (WHO). (2017). Community-based rehabilitation (CBR). Retrieved from <http://www.who.int/disabilities/cbr/en/>

World Health Organization (WHO). (2010). CBR matrix. Retrieved from http://www.who.int/disabilities/cbr/cbr_matrix_11.10.pdf?ua=1

Young, R., Grills, N., Reeve, M., Devine, A., & Singh, L. (2016). A realist evaluation of the formation of groups of people with disabilities in Northern India. *Christian Journal for Global Health*. 3(2), 72–90.

 ‘With Hope to Help Ourselves and Others’: The Impact of Disabled People’s Organisations on the Lives of Persons with Disability in Uttarakhand, North India by [Michelle Leung, Alexandra Devine, Lawrence Singh, Teem-Wing Yip, & Nathan Grills](#) is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <https://rdsjournal.org>. Permissions beyond the scope of this license may be available at <https://www.rds.hawaii.edu>.

Research Article

Job-Related Challenges of Teachers with Physical Disabilities in Kumasi

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Abstract: This study aimed to establish the job-related challenges of Teachers with Physical Disabilities (TWPDP) within the Kumasi Metropolitan Education Unit in Ghana. Twenty-one (21) TWPDPs completed the study. A cross-sectional study design was used and an interview guide was utilized to solicit responses. Thematic content analysis was employed in analyzing the data collected. Relative to the nature of impairment, ‘pain’ and ‘weakness’ emerged in relation to impairments associated with TWPDPs. ‘Mobility on school compound’ and ‘writing on the board’ were specific task related challenges encountered by TWPDPs. However, additional job-related challenges existed in the form of attitudinal barriers. Due to the prevailing job-related challenges, most TWPDPs had employed specific coping mechanisms to offset some of the challenges. Prominent among these coping mechanisms were being dependent on others for physical support and taking frequent breaks from tasks that were physically demanding. Overall, most TWPDPs asserted they felt disadvantaged compared to their colleagues without physical disabilities due to the numerous job challenges they encountered. In light of these, it is recommended that the Ghana Education Service (GES) should profile the respective work-related challenges of TWPDPs to come up with policies and interventions that would gradually eliminate these challenges.

Keywords: Job-Related; Challenges; Teachers; Physical Disabilities; Kumasi

Introduction

The term ‘physical disability’ (PD) is defined broadly to cover a wide range of disabilities and health-related issues, including both congenital and acquired disabilities (Belson, 2003). Conditions that may pass for physical disabilities include muscular dystrophy, leg-length discrepancies, amputations, third-grade nerve injuries, spinal cord injuries and chronic fatigue syndrome. Other conditions such as cerebral palsy, spina bifida, arthritis, multiple sclerosis, stroke and auto-immune diseases could lead to physical disabilities. PD typically manifests in the form of restrictions in physical activities including walking, ability to negotiate obstacles, difficulties with using common tools and equipment and easy fatigability (Cockerham, 2007).

According to the World Health Organization (2011), of the one billion of the world’s population that has a disability, 80 million of them live in Africa, 737,743 of those in Africa live in Ghana (Ghana Statistical Service, 2012). Nearly 150 million persons with disabilities in the world experience extremely dire difficulties in life.

Persons with Physical Disabilities (PWPD) have different job-related experiences that

typically depend on the type of job and availability or otherwise of barriers/facilitators. Generally, PWPDs tend to face fewer challenges with jobs that are not physically demanding compared to jobs that demand more physical effort (Bredberg, 1999). The foremost challenge of most PWPDs relative to their jobs has to do with access to the workplace. The presence of barriers in the form of staircases, lack of elevators, lack of handrails and ramps at the workplace implies PWPDs expend more effort in reaching their respective offices. In research by Erb and Harriss-White (2002), the majority of PWPDs surveyed admitted to the presence of barriers that hindered their entry to their respective points of work. In a similar survey by Ghai (2003), women with physical disabilities conceded the presence of facilitators would greatly improve accessibility to their respective workplaces. On some rare occasions, the lack of accessibility to workplaces resulted in PWPDs being dependent on other co-workers to access their respective offices (Jeffery & Singal, 2008).

Kalyanpur (2007) found that teachers within the New Delhi metropolis felt the lack of physical facilitators within their respective schools and the metropolis hampered their performance relative to classroom work. In research by Obiozor (2010), some teachers with disabilities felt that less was expected of them at their respective workplaces due to their disabilities. Although this attitude might appear empathic, most of the TWPDs felt it was because they were thought of as 'weak'.

Teachers play a huge role in shaping and mentoring students not just for academic success, but for life in general. Challenges that have the potential to negatively impact the competence or work of teachers are likely to undermine the aforementioned mentorship role and endanger the academic success of students. Thus there is a need to thoroughly assess the job-related challenges of teachers with disabilities to proffer long-term solutions that would enhance the competence of these teachers as well as ensure their students do well academically.

Methods

Study Site

The Kumasi Metropolitan Education Unit (KMEU) is responsible for 551 schools within the Kumasi metropolitan area in Ghana. These schools are made up of 158 kindergarten schools, 205 primary schools, and 188 junior high schools. There are over 4,000 teachers working in the metropolitan unit. TWPDs constitute of less than 1% of all teachers within the unit. The KMEU serves as the administrative center for these schools and ensures that the teaching and learning in these schools is consistent with the dictates of the Ghana Education Service (GES).

Additionally, the Metropolitan Education Unit enforces the policies of the GES related to compensation of teachers with disabilities. Teachers with physical disabilities are entitled to a 'disability allowance' that is paid monthly as part of their monthly remuneration. However, there are no teacher-specific policies that are directed towards making the job of teachers with physical disabilities any friendlier at the Metropolitan Education Unit level. Job-

related challenges of teachers with physical disabilities are typically reported to the highest school authority for remedial actions.

Study Design and Approach

A cross-sectional design and a qualitative approach was adopted for the study. Cross-sectional design allows for studies to be conducted over a relatively shorter period of time and are usually cost-effective (Hatch, 2002). With respect to this study, a cross-sectional design was the best approach. A major disadvantage of cross-sectional design is the fact that the timing of the snapshot might not be representative of the study population (Creswell, 2009).

Relative to this research, the emphasis was put on unearthing the ‘meaning’ of the work-related challenges of teachers in an in-depth manner. Thus the choice of a qualitative approach was the best option as it allowed for a free-flowing narrative in which teachers thoroughly expressed themselves. Additionally, adopting a qualitative philosophy allowed for more probing questions that the researcher might not have initially considered. The job-related challenges of TWPDs is a complex issue that ranges from the obvious such as physical barriers to the very subtle such as difficulties in using teaching materials. Other advantages of qualitative research include the fact that it is not limited to rigidly defined variables and draws on the compelling experiences of respondents (Creswell, 1998).

Study Population and Inclusion Criterion

The study population consisted of all teachers with physical disabilities within the Kumasi Metropolitan Education Unit. The Metropolitan Education Office keeps information of all teachers with physical disabilities for policy and management purposes. Additional inclusion criterion involved teachers having practiced for at least a year. This was to ensure respondents had some level of experience in the rudiments of their work. Further to this, the aforementioned inclusion criterion raised the chances that respondents would have encountered some challenges relative to their work.

Sampling Technique and Size

A purposive sampling technique was employed in this study to select teachers with physical disabilities. The aforementioned sampling technique allows a researcher to reach his/her targeted sample over a relatively short period of time, while allowing for a variety of research designs to be utilized (Morse et al., 2002). With respect to this study, TWPDs were the target participants and due to their relatively low numbers, a purposive sampling approach allowed for the majority of them to be included in the study. The disadvantages of purposive sampling include possible researcher bias in selecting participants and the lack of representativeness relative to the sample (Kuckartz, 2014).

For qualitative research, samples must be large enough to allow for all unique perspectives on an issue to be covered. However, if the sample becomes too large, the data are likely to be repetitive and subsequently, superfluous.

The sample size for this study was based on the concept of saturation as espoused by Morse (2001). By this concept, saturation is achieved when adding more respondents to the study that does not add any new perspective to the information collected. With respect to this study, no new perspectives were discovered beyond the first 21 respondents. Relative to the nature of impairment, 'pain' and 'weakness' were repeated by three (3) respondents beyond the 21st respondent. Other issues that were repeated by the aforementioned respondents included challenges with mobility on school compounds and difficulties with teaching materials.

Research Instruments

The study utilized an interview guide. Information relating to demographic characteristics of respondents was sought using closed questions while those related to the specific objectives of the research utilized open-ended questions. A major advantage of using an interview guide is the fact that it allows for easy flow of the conversation between the researcher and respondent while giving the opportunity for the researcher to ask more probing questions (Creswell, 1998). More probing questions were asked based on respondents' answers to specific questions. The essence of the probing questions was to unearth the 'true' meaning of respondents' answers which is consistent with qualitative research.

Report on the Pilot Study

A pilot study was carried out to test the overall feasibility of the study as well as streamline the questions in the interview guide. The pilot study was carried out at the Ejisu Juaben Municipal Education Unit with 10 teachers with physical disabilities completing the interview schedule. It was discovered that respondents experienced varying impairments that were mainly associated with an arm or leg. Pain and weakness were the major manifestations of the underlying impairments. Pain, in particular, was discovered to interfere with the activities of TWPDs and on certain rare occasions, halted the execution of specific physical activities. The majority of respondents felt the impairment they experienced did not interfere with most of their job-related activities. A common improvised method employed by respondents in overcoming difficult physical activities involved soliciting the help of pupils.

Physical barriers confronting TWPDs included inaccessible classrooms and a general lack of reasonable accommodation within classrooms. Specifically, staircases, non-adjustable seats, fixed writing boards were common physical barriers cited by TWPDs. Overly sympathetic behaviors from colleagues and students, students' fixation on teachers' physical disabilities, lesser expectations from higher authorities were some of the major attitudinal barriers pilot respondents admitted to. Most pilot respondents believed that the policies of the Ghana Education Service on TWPDs hardly addressed the challenges within the classrooms. In terms of the aforementioned challenges on the performance of TWPDs, most respondents felt the challenges did not negatively impact their overall competence as teachers.

Overall the pilot study informed a re-arrangement of the questions in the interview guide to allow for a better flow of the conversations based on respondents' answers.

Additionally, it allowed the researcher to anticipate the explaining technical terms such as disability and impairment.

Field Data Collection

Data collection for this study took approximately two months to complete. The interviews took place within the premises of respondents' respective schools. TWPDs chose the most convenient time to have an interview with the researcher. The interview sessions usually lasted 30 minutes per respondent with an audio recording of the entire session. Respondents first completed demographic questions, followed by the nature of their impairment and finally job-related challenges. Grey areas were clarified based on respondent's probing questions. Similarly, based on the respondent's answers, the researcher probed further in instances where answers lacked clarity.

Data Management and Analysis

To ensure the integrity of data, all audio recordings were played back on the same day of recording by the researcher to ensure clarity of responses to questions. Additionally, all recordings were uploaded on google drive for backup purposes, safe-keeping, and easy retrieval.

Data analysis involved thematic analysis that utilized the six procedures; familiarization with data, forming initial codes, identifying themes within codes, reviewing themes, naming themes and creating the final report.

In the familiarization with the data stage, all audio recordings were transcribed verbatim into written format. Generating the initial codes involved identifying recurring patterns within the transcribed data. These recurring patterns were not based on mere words but based on the 'true' meanings of respondents' answers to questions. Within the initial codes, themes were further identified and the relationship between themes identified. Reviewing the themes involved establishing a link between the themes and the literature review undertaken for the research. This was to ensure that there was literature to support and expand the generated themes. The final report of the thematic analysis is reported in the next chapter and is consistent with research objectives.

Validity

To ensure the validity of the interview guide, questions were made consistent with the study objectives. Questions were reworded in line with established concepts of disability and challenges usually encountered by persons with physical disabilities. Questions were exhaustive enough to cover all study objectives and put in simple clear language. Further to this, the research questions of previous studies related to the challenges of persons with physical disabilities by Bredberg (1999); Horstman et al. (2008); and Jeffery and Singal (2008) were thoroughly studied to ensure some of the questions asked in these previous studies were consistent with those in this study.

Reliability

The aforementioned pilot study ensured the reliability of the research instrument (interview guide). Grey areas of the interview guide were thoroughly rephrased and made consistent to ensure respondents were in no doubt as to the meaning of the questions. These grey areas were considered for modification whenever at least two pilot respondents sought clarity on a particular question. Specific questions that were modified to improve consistency included those related to attitudinal barriers, policies of the GES and the perceived disadvantages TWPDs encountered.

Ethical Consideration

Ethical approval was sought and granted by the ethics committee of the Committee on Human Research, Publications and Research (CHRPR) of Kwame Nkrumah University of Science and Technology. Ethical approval was also sought and granted by the Kumasi Metropolitan Education Unit. Respondents and the researcher signed an informed consent form. The consent form detailed the process of the research, potential benefits as well as the potential harm that could arise from it. Pseudonyms were used to mask the identities of respondents while ensuring participants could be reached in case further clarification on responses was needed. Further to this, respondents were assured of their right to withdraw from the study at any time if they wished.

Proper record keeping and storage ensured confidentiality of data related to respondents. Additionally, transcribed data were kept on the researcher's computer with a password.

Results

4.1 Socio-Demographic and Disability Characteristics of Respondents

Table 1 presents the socio-demographic and disability characteristics of respondents. Males formed the vast majority (71.43%) of respondents. Less than a quarter (23.81%) of all respondents had a Diploma qualification, the remainder had a Bachelor's (61.90%) or a Post-Graduate (14.29%) qualification. Lower-limb (leg) disability (71.43%) was the most prevalent form of disability. Nearly half (47.62%) of all respondents did not use an assistive device. However, lower limb assistive devices were the most commonly used (38.09%).

Table 1 *Socio-Demographic and Disability Characteristics of Respondents*

Age in years (Mean ± SD)	40.20 ± 4.5
Gender	
Male	15 (71.43%)
Female	6 (28.57%)

Years of practice (Mean ± SD)	15 ± 6.41
Highest educational attainment	
Diploma	5 (23.81%)
Bachelor's degree	13 (61.90%)
Post-graduate degree	3 (14.29%)
Teaching Level	
Primary	9 (42.86%)
Junior High	12 (57.14%)
A body part with disability	
Upper limb (arm)	5 (23.80%)
Lower limb (leg)	15 (71.43%)
Trunk	1 (4.76%)
Type of assistive device	
None	10 (47.62%)
Arm support	1 (4.76%)
Leg support	8 (38.09%)
Wheelchair	2 (9.52%)

Nature of Impairment and its Effects Among Teachers

Relative to how the underlying impairment was manifested, two major themes emerged; 'pain' and 'weakness'. The majority of respondents felt that pain was a major debilitating factor in their respective physical disabilities. Respondents gave different accounts of the type of pain and the associated weakness they experienced. While some respondents described the pain as sharp and shooting, others suggested the pain they experienced was dull and aching. For some respondents, the occurrence of pain was occasional; while others explained the pain was more persistent and disrupted their everyday activities. Oduro stated that:

The feeling of pain from my right leg is the most difficult symptom I experience; the pain is present most of the time and I do not have to exert myself to experience it.

Kofi stated:

I experience a dull aching pain that makes me weak in the left elbow and shoulder when I raise my arm; the pain is usually severer in the mornings compared to other times of the day.

Most respondents with lower limb physical disabilities further alluded that the pain experienced in the affected limb typically radiated to the lower back as well. This phenomenon, they believed was due to the compensatory mechanisms they adopted in order to overcome the physical challenges associated with their respective disabilities. Mansa reaffirmed:

Due to the state of my right leg being shorter than the left, I tend to put more weight on the right half of my body. This has resulted in my spine taking a more curved appearance and as a result, I feel lots of pain in my lower back.

Additionally, the vast majority of respondents believed the pain and associated weakness affected their overall physical endurance to such an extent that they were unable to cope with numerous everyday physical activities. As noted by Kwame:

Due to the constant pain and weakness in my left thigh, I do not feel fit at all as I easily get tired walking the shortest of distances.

Beyond the symptoms associated with the primary impairment, another trend that emerged was pain and weakness that were associated with the use of assistive devices and compensatory mechanisms. For example, a good number of respondents with lower limb physical impairments who utilized axillary crutches as assistive devices reported experiencing painful shoulders due to pressure from the axillary crutches as Kwadwo highlighted:

Aside from the pain from my leg, I do experience lots of pain from my right shoulder due to the fact that I have been on these crutches for several years.

Job-Related Challenges of Teachers

In relation to the specific job-related tasks that proved most challenging, 'mobility on school compound' and 'writing on the board' emerged as major themes. Teachers explained that they encountered numerous physical barriers within school compounds that impeded their movements between classrooms. Prominent among these physical barriers were uneven floors, lack of concrete floors, lack of ramps, and presence of staircases at the entrances to some classrooms.

Uneven floors generally made the use of assistive devices very difficult. On some occasions, the imbalance it produced led to the tripping of some teachers on axillary crutches, with the potential for serious injury. Amponsah succinctly explains:

My biggest job-related challenge is movement on the school compound with my crutches, the uneven floor makes me lose balance occasionally and I have actually

fallen thrice since I started work.

Additionally, respondents explained that the lack of concrete floors in some schools made it extremely challenging to use assistive devices as well as increased their chances of tripping. This situation was made worse on days when it rained, as there was virtually no grip between the floor and the tip of walking aids. The lack of ramps on school compounds made it extremely difficult for teachers to navigate their way around school compounds. Among respondents, wheelchair users complained the most about the lack of ramps on school compounds; however, teachers who utilized crutches equally explained the lack of ramps and presence of staircases posed serious ambulatory challenges for them. Afia, who uses a tricycle propelled with the upper limbs, asserted:

With my tricycle, I usually have to switch to crutches and get the assistance of another person before I am able to negotiate the staircase in front of my classroom.

With respect to the challenges of writing on classroom boards, nearly all respondents admitted to one challenge or the other. For respondents on axillary and elbow crutches, the relatively higher placed boards meant they were unable to have the maximum support of their respective assistive devices as they had to stretch to write on the board. Akenten captured this as:

Writing on the board poses a lot of problems for me as I have to lift my arm from my elbow crutches while I reach for the board; this makes me feel highly unstable with respect to my balance.

For respondents who utilized wheelchairs, the situation was even worse. They admitted to being able to use only the lower margins of writing boards within their respective schools due to the fact that the writing boards were fixed and not adjustable.

Beyond task-specific challenges, other challenges for teachers with physical disabilities existed, mainly in the form of attitudinal barriers. However, most teachers admitted stigmatization of their respective conditions was rare at the workplace. Rather, it was an avalanche of 'sympathy from colleagues and students' that they believed negatively affected their respective work. This overly sympathetic attitude, they asserted, led to colleagues, students, and superiors expecting less from them. As captured by Kwame:

Consistently when I present my lesson notes to the headmaster, he tends to pass it off quickly while he does a lot of criticism on that of my colleagues. Initially, I felt it was because my notes were better, only to detect that I committed the same errors as my colleagues.

Most teachers felt the attitude of expecting less from them generally made them feel helpless and acted against building their confidence. Sympathetic behavior from other teachers and students often came in the form of unsolicited physical support. Teachers complained that on most occasions when they tried some physical tasks, there were numerous colleagues and sometimes students on hand to take over. While a few teachers with physical

disabilities thought this attitude was beneficial to them, the majority felt it negatively impacted on their confidence in terms of executing physical activities.

With respect to specific Ghana Education Service (GES) policies towards teachers with physical disabilities, most respondents thought they were woefully inadequate. Beside a paltry 'disability allowance' that is paid as part of their monthly salary, teachers felt the barriers hampering their work in their respective schools were hardly addressed. Teacher specific challenges such as inaccessible classrooms due to the lack of ramps, non-adjustable writing boards and inaccessible washrooms that had been reported to the GES by headmasters had largely not been addressed. Teachers explained that headmasters often alluded to the fact that the GES does not have readily available funds to eliminate the aforementioned barriers, but with the introduction of inclusive education, most of these barriers would be removed. However, with the passage of time and the deadline for all schools to be fully inclusive having expired, teachers are yet to see any concrete measures relative to the removal of work-related barriers.

Coping Mechanisms Adopted by Teachers

Teachers admitted to employing numerous improvised methods to overcome the difficulties associated with specific work-related tasks. 'Support from colleagues and students' and 'taking frequent breaks' were the major themes that emerged. Teachers admitted to being dependent on colleagues on occasions when they had to negotiate physical barriers to their respective school compounds. This dependence often came in the form of physical support which occasionally required more than one colleague. Kumi stated:

To make my way to the staffroom, I usually have to wait on my colleague who sometimes calls in a second colleague due to the fact that the staircase leading to the room is quite expansive.

With respect to making maximum use of the writing boards, teachers who reported difficulties admitted soliciting the support of students. These students often wrote on the board for the teachers while class was in session.

Taking occasional breaks from specific tasks was equally an effective strategy used by some teachers in order to overcome specific work-related tasks. These teachers explained that they often took breaks to relieve themselves of the severe discomfort they felt in performing those activities. Teachers generally admitted the aforementioned improvised methods were often successful but came at a huge cost. As Kumi stated:

Due to the fact that I mostly wait on my colleagues before accessing the staffroom, I usually lose several minutes and sometimes a whole hour of work at the office.

Effects of the Challenges on the Work of Teachers with Physical Disability in the Kumasi Metropolitan Education Unit

Professionally, teachers generally felt they were ‘somehow disadvantaged’ due to their physical disabilities. They recounted numerous opportunities they missed due to their respective physical disabilities. Opportunities for professional development, workshops and seminars were missed because school authorities felt they were too physically demanding for TWPDs. Additionally, teachers felt their chances of a transfer to a desirable school were greatly reduced as the school would have to be closer to their residence. Oforiwa emphasized that:

There are some few schools within the metropolis with great opportunities that would have enhanced my career, but they are quite far from my residence and as such working there would be challenging.

The vast majority of teachers equally felt they wielded less influence in terms of exerting control of their respective classes. This they believed was due to their limited mobility which sometimes made it difficult for them to enforce class rules. Additionally, they admitted the fact that they depended on students to run numerous errands did impact on enforcing strict class rules. Yaw put it as:

I honestly find it difficult strictly enforcing the class rules, as a rule as I generally have a liberal relationship with the majority of my class members; they help me out on a lot of physically demanding tasks.

In spite of the numerous improvised methods teachers employed to minimize the effects of their respective physical disabilities; most teachers believed they would have performed a lot better on their respective subjects if the appropriate physical facilitators were in place. Kwadwo explained that:

My job as a mathematics teacher demands I write a lot of illustrations on the board; due to the relatively higher position of the board, I am forced to stand over extended periods of time. This makes me very tired and affects my overall performance.

In relation to punctuality, most teachers asserted they were usually ‘punctual’ despite the numerous physical barriers they encountered. Adopted strategies to avoid lateness included setting off early and avoiding congested areas when heading for their respective schools. Further to this, most teachers admitted their respective physical disabilities rarely made them miss school.

In spite of the several challenges, most teachers felt they were ‘competent’ in their respective roles. They explained that the stellar academic performance of their respective classes was proof that the underlying physical impairment and associated challenges had not affected their competencies. Personally, most teachers admitted to being ‘confident’ of their abilities as teachers and recounted how they are able to partake in organizing co-curriculum activities such as sports. Kumi asserted:

I honestly believe I am as competent as any of my colleagues; over the past years students taking my course have generally done well and I am able to accomplish most co-curriculum activities assigned me.

Discussion

The high incidence of pain among TWPDs is consistent with the findings of Wade and de Jong (2000) who reported pain to be one of the most common debilitating occurrences affecting persons with physical disabilities. The issue of pain has a number of implications. Firstly, the uncomfortable nature of pain could further derail the levels of physical functioning of affected teachers as more effort is expended on routine activities when working through the pain barrier. Thus a vicious cycle sets in which TWPDs who find physical functioning quite demanding are further compromised by pain. This is likely to give rise to fatigue with the potential to impact on the overall work performance of affected teachers. This phenomenon probably explains why the majority of TWPDs who experienced pain equally reported weakness as a concomitant debilitating factor. Secondly, as posited by Muse (2002), long-term pain has the potential to make affected persons irritable, short-tempered and impatient. The aforementioned negative attributes could undermine their work and more importantly, negatively impact the academic performance of their respective students.

Pain associated with the usage of assistive devices could cause TWPDs to use those devices less frequently. It is also possible for some TWPDs to completely abandon such assistive devices (Phillip & Zhao, 1993). Indeed, this could be responsible for the relatively higher number of respondents in this study who did not employ an assistive device. As posited by Ostir et al. (2002) assistive devices generally enhance the functional independence of persons with disabilities by providing additional support, boosting feelings of safety and raising confidence. Thus in both instances, affected teachers are likely to lose some level of functional independence and are likely to depend on the physical support of others with long-term negative implications for their respective jobs. Additionally, non-usage of assistive devices could give rise to more compensatory gait mechanics such as 'stooping' with the possibility of inducing more pain.

The general absence of physical facilitators such as walkways, ramps, curb ramps and handrails within the environs of TWPDs could equally account for nearly half of respondents who did not use assistive devices. As asserted by Sah (2010), assistive devices should be coupled with the provision of facilitators to allow for the optimal physical functioning of PWDs. For example, teachers using wheelchairs, walkways would ensure there was sufficient space for mobility while curb ramps would ensure they were able to join adjoining roads. In the absence of these facilitators, the use of a wheelchair for mobility is extremely difficult and on some occasions, virtually impossible. Accommodations for teachers, including ramps and better flooring, would help students as well as visitors to the school. As such they can be perceived to be more cost-effective than they might seem if the focus was only on teachers.

As asserted by Bredberg (1999), PWPDs generally find jobs that are 'physically demanding tough to cope with'. Teaching, by its very nature, demands constant interaction with students and the school environment that may prove physically demanding. Difficulties with mobility on school compounds due to the lack of facilitators suggests that affected teachers were less mobile on campus due to possible discomfort associated with mobility. This could have a negative impact on building interpersonal relationships with colleagues. Such interpersonal relationships are important for teachers to share ideas and relieve job-related stress. As espoused by Mayo et al. (1999), in the absence of interpersonal relationships at work, feelings of depression and helplessness could set in and negatively impact the work of teachers. On occasions where affected teachers are obliged to move, such as having a class in an adjacent block, uneven floors, and lack of ramps could raise the risk of tripping with possible injuries that could derail the health of the affected TWPDs. As reaffirmed by the Heart and Stroke Foundation (2017), facilitators do not only ensure better physical performance by PWPDs but ensure their safety as well.

On the other hand, the lack of facilitators such as ramps, as deduced by Jeffery and Singal (2008), could force teachers to be dependent on other people for their mobility. These teachers are likely to be stranded or lose precious time on the days that these persons are not readily available. Further to this, teachers, being dependent on other people for mobility feeds into the perception that PWDs (including affected teachers) are helpless and mask the issue of a lack of facilitators.

Additionally, decreased mobility among TWPDs, as suggested by Horstman et al. (2008), could give rise to physical deconditioning in which the affected teachers' physical endurance further diminishes due to the lack of physical activity. This could have long-term negative implications for affected teachers' ability to move, even when utilizing assistive devices.

The widespread issue of difficulties with using the writing board is of grave concern as it is a basic tool of communication between teachers and students. Teachers in wheelchairs who utilized only the lower margin of the writing boards suggests that these teachers had only a limited space to share information with students. In the absence of teaching assistants, these teachers are likely to utilize the services of some students in writing out notes on the board. This unorthodox approach would likely have a negative impact on teaching and learning. The student who volunteers to write on the board would have to make extra time to write out his/her personal notes. This has the tendency to affect the general class organization as well as burden those students who volunteer to write on the board. For teachers who felt unstable on their crutches due to the fact that they had to stretch to reach relatively high writing boards, the situation puts them at risk of falling due to the lack of body balance created. Moreover, affected teachers were likely to be fatigued as it takes more physical effort to maintain their balance without the maximum support of their crutches.

Improvised methods by TWPDs such as taking occasional breaks suggest these teachers took a longer time to accomplish work-related tasks. On occasions where time was

limited, affected teachers were likely not to accomplish these tasks with the potential to affect their overall performance as well as that of their students.

As asserted by Minow (1990) sympathetic behavior towards PWDs are usually founded on the perception that such persons are helpless. Sympathetic behavior from colleagues and school authorities expecting less from TWPDs could negatively impact their overall competencies as teachers. For example, lesson notes are strictly planned based on curriculum content, student needs, and teaching strategies. Subsequently, if these lesson notes are not thoroughly inspected by the appropriate authorities as admitted by some respondents, teachers are bound to develop a lacklustre attitude towards such an important exercise. With the passage of time, this lackluster attitude becomes entrenched and has the potential to negatively impact affected teachers' professionalism. Additionally, students' academic performance could suffer if teachers' competencies are compromised.

Sympathetic behavior towards PWDs tends to discount their contributions and frustrates their efforts in improving their work output (Nambissan, 2000). For hardworking TWPDs who get results, the sympathetic behavior could mean they are not appreciated as their outputs are never critically examined. Subsequently, there is no motivation to improve.

The lack of policies by the Ghana Education Service (GES) to address specific problems encountered by TWPDs implies these problems are likely to linger on over the long term. As the regulatory body responsible for the management and development of schools and their human resources, the lack of clear-cut policies on catering for the needs of teachers with disabilities implies school authorities are at a loss as to whether to report on barriers hampering such teachers. For school authorities who take the initiative to report on such issues, the lack of clear-cut policies on supporting teachers with disabilities means the GES does not have the budget to support such reports. The reports become mere formalities and over time, school authorities are likely to give up and not forward these reports to the GES. With respect to TWPDs, this situation creates a feeling of hopelessness and could lead to psychological problems alongside the pertaining physical challenges. The disability allowance paid to TWPDs does little to solve the numerous challenges confronting teachers as they are meant for personal use while the majority of the aforementioned challenges confronting teachers are job-related.

The general feeling of being disadvantaged by TWPDs is a testament to the widespread barriers (both physical and attitudinal) they faced relative to their jobs. The numerous professional development opportunities missed by TWPDs points to the fact that school authorities view the challenges confronting these teachers as emanating from them and not due to the lack of facilitators, alluding to the normal-abnormal categorization as espoused by Lányi et al.(2004). In the aforementioned categorization, the barriers associated with disability (including physical challenges) emanate from the individual person with a disability and the expectations for he/she to cope.

TWPDs admitting to having less control of their respective classes due to their lack of mobility within classrooms have far-reaching implications for their respective jobs. Firstly,

the situation of lack of class control could lead to students not having the full import of lessons as a class could potentially be easily disrupted. Additionally, classroom misbehavior such as avoidance of work, clowning, harassing classmates, verbal abuse and defiance could become entrenched with the passage of time. The aforementioned misbehavior on the part of students would most likely negatively impact on the academic performance of students while creating the impression TWPDs were not up to the task.

Subject-specific challenges of TWPDs due to the lack of physical facilitators could demotivate teachers and affect students' enthusiasm towards those subjects and subsequently their academic performances on those subjects. Despite teachers believing they were competent and alluding to the stellar academic performances of their respective students, the existence of subject-specific challenges implies students' performance in these subjects could improve if the associated barriers were eliminated. Additionally, the persisting physical challenges in teaching these subjects could force affected teachers to adopt less stressful postures towards those subjects. For example, in the classic case of Nkansah the mathematics teacher, taking a seat and utilizing the lower margin of the writing board would be more comfortable than the prolonged standing he has to endure. However, this is likely to negatively impact on his lesson delivery as teaching mathematics requires writing out systematic illustrations in order for students to comprehend the concepts.

Limitations

A major limitation of the study is the fact that the relatively small numbers of TWPDs available in the Kumasi Metropolitan Education Unit would not allow for the application of probability sampling, thus limiting the extent to which the study findings could be generalized. Also, there are no such studies on TWPDs available in developing countries to compare with the findings from this study.

Conclusion

In conclusion, the numerous job-related challenges TWPDs encountered in this study mirror the challenges of PWPDs in Ghana in which issues of disability and disablement are often not prioritized by policymakers. This is often exacerbated by cultural stereotypes in which PWDs (including TWPDs) in general are seen as helpless and needing the support of others. Thus a vicious cycle is created where the absence of facilitators make TWPDs more vulnerable, and consequently, adopt unorthodox means of overcoming the barriers to their respective jobs. This, in turn, reinforces the stereotypes against them and masks the real issues militating against their respective jobs.

Recommendations

In light of the findings of inadequate policies by GES, it is recommended that the GES, in addition to collecting information on TWPDs, should profile their respective work-related challenges. This profiling would give a vivid description of the varied and respective physical challenges that could form the basis of long-term policies towards eradicating the

numerous barriers that confront these teachers. Additionally, the profiling would allow for prioritizing some challenges over others in the face of a limited budget. For example, issues of accessibility to the workplace could be prioritized over classroom challenges if it is discovered more teachers have challenges with accessing the workplace. Thus with the passage of time, most barriers would be removed in order of their respective frequency of occurrence among teachers. This profiling should commence as soon as feasible and should directly involve officers of the GES and TWPDs.

Secondly, the GES, with its' specialist disability staff could embark on sensitization programs on the concept of reasonable accommodation within the various schools. This would ensure stakeholders (including teachers, headmasters, and Parent-Teacher Associations) contribute to interventions that would ensure the gradual removal of the numerous barriers confronting TWPDs. For example, PTAs of the respective schools could possibly raise funds to procure adjustable writing boards that would cater for the difficulties associated with writing boards confirmed by some TWPDs. This sensitization program could be carried out once a year by the respective schools within the metropolitan education unit.

With respect to the avalanche of sympathetic behavior towards TWPDs, advocacy on the social construction of disability would help improve stakeholders' attitudes towards TWPDs. Stakeholders should be made to understand that if the appropriate facilitators are in place, TWPDs could be physically independent. Thus the avalanche of sympathy is misdirected as TWPDs are not primarily responsible for the physical challenges encountered. Disability campaigners, for example *Disability Talkers* in Kumasi, would be a very appropriate body to embark on the aforementioned advocacy. This could be done through seminars periodically and should commence as soon as feasible.

The finding that TWPDs missed out on a number of professional development opportunities suggests forming a self-help group, this could work to increase their chances of professional development. Firstly, the self-help group could lobby organizers of teacher-related workshops and seminars to make provisions for TWPDs while engaging school authorities to nominate them for such endeavors. Additionally, self-help groups could enable TWPDs to share valuable experiences that would enhance their roles in their respective schools. The self-help group could be formed as soon as feasible.

Furthermore, the problems related to difficulties with writing on the board, could be handled with technological accommodations that are now relatively cheap to provide. The Ministry of Education could support this initiative by making the technologies available.

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Disclosure Statement

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References

- Belson, S. I. (2003). *Physical disabilities*, NY: Houghton Mufflin Inc.
- Bredberg, E. (1999). *Writing disability history: Problems, perspectives and sources*. Disability & Society, 3rd Edition. London: Sage Publications, Inc.
- Cockerham, W. C. (2007). *Social causes of health and disease*. Cambridge, UK: Polity Press.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications, Inc.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. 3rd edition. Los Angeles: Sage Publications, Inc.
- Erb, S., & Harriss-White, B. (2002). *Outcast from social welfare: Adult incapacity and disability in rural South India*. Bangalore: Books for Change.
- Ghai, A. (2003). *(Dis)embodied form. Issues of disabled women*. New Delhi: Shakti Books.

- Ghana Statistical Services. (2012). *Population & housing census: Summary report of final results 2010*. Accra, Ghana: Ghana Statistical Service.
- Hatch, J. A. (2002). *Doing qualitative research in education settings*. Albany: SUNY Press.
- Heart and Stroke Foundation. (2017). *Interventions for Stroke*. Retrieved from www.strokengine.ca/intervention/assistive-devices
- Horstman, A. M., Beltman, M. J., Gerrits, K. H., Koppe, P., Janssen, T. W., Elich, P., & Haan, A. (2008). Intrinsic muscle strength and voluntary activation of both lower limbs and functional performance after stroke. *Clinical Physiology and Functional Imaging*, 28(4), 251–261.
- Jeffery, R., & Singal, N. (2008). Disability estimates in India: A changing landscape of socio-political struggle. *Economic and Political Weekly*, 43(12 & 13), 22–24.
- Kuckartz, U. (2014). *Qualitative text analysis: A guide to methods, practice and using software*. Sage Publications, Inc.
- Kalyanpur, M. (2007). *Equality, quality and quantity: Challenges in inclusive education*. Sage Publications, Inc.
- Lányi, C. S., Laky, V., Tilinger, A., Pataky, I., Simon, L., Kiss, B., ... & Páll, A. (2004). Developing multimedia software and virtual reality worlds and their use in rehabilitation and psychology. *Studies in Health Technology and Informatics*, 105, 273–284.
- Mayo, E. N., Wood-Dauphinee, S., Ahmed, S., Carron, G., Higgins, J., Mcewen, S., & Salbach, N. (1999). Disablement following stroke. *Disability and Rehabilitation*, 21(5&6), 258–268.
- Minow, M. (1990). *Making all the difference. Inclusion, exclusion and American law*. Cornell: University Press.
- Morse, J. M. (2001). Situating grounded theory within qualitative inquiry. In R. S. Schreiber & P. N. Stern (Eds.), *Using Grounded Theory in Nursing* (pp. 1–15). New York: Springer Publishing Company, Inc.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13–22.
- Muse, M. (2002). Stress-related, posttraumatic chronic pain syndrome: Behavioral treatment approach. *Pain*, 25(3), 389–94.
- Nambissan, G. B. (2000). Dealing with deprivation. *Enabling Education*, 25(3), 389–94.
- Obiozor, W. E. (2010). The Use of Music to Teach Life Skills to Students with Emotional Disabilities in the Classroom. *Online Submission*, 7(1), 17–26.
- Ostir, G. V., Goodwin, J. S., Markides, K. S., Ottenbacher, K. J., Balfour, J., & Guralnik, J. M. (2002). 'Differential effects of premorbid physical and emotional health on recovery from acute events'. *Journal of the American Geriatrics Society*, 50(4), 713–

718

Phillip, B., & Zhao, H. (1993). Predictors of assistive technology abandonment. *Assistive Technology*, 5(1), 36–45.

Sah, P. K. (2010). Assistive technology competencies: Need, outlook, and prospects (with reference to special educators for children with visual impairment). *American Journal of Disability*, 200(15), 22–35.

Wade, D. T., & de Jong, B. A. (2000). Recent advances: Recent advances in rehabilitation. *British Medical Journal*, 320(7246), 1385.

World Health Organization, and World Bank. (2011). *World report on disability 2011*. Geneva, Switzerland: World Health Organization.



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Creative Works

Kū Kanaka: Stand Tall

A Conversation with Filmmaker Marlene Booth

(with RDS Multimedia and Creative Works Editor, Raphael Raphael)

Raphael Raphael, PhD

*Review of Disability Studies: An International Journal Associate Editor of Creative Works
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Abstract: In this short interview, filmmaker and educator Marlene Booth discusses her work on the documentary *Kū Kanaka: Stand Tall* about the life of disabled Native Hawaiian activist Kanalu Young. She also discusses her friendship with Young as well as her own creative practice.

RR: What initially inspired you to create *Kū Kanaka: Stand Tall*?

MB: I had worked with Kanalu Young on an earlier film, *Pidgin the Voice of Hawai‘i*. As we were finishing that film, Kanalu passed away. I found myself thinking about Kanalu and how he became the man he was. Eventually, I decided that I wanted to make a film about him.

RR: Can you say a bit about your personal experience knowing and working with Kanalu before creating a film about him?

MB: I first met Kanalu in 2000 when we both served on a panel judging film proposals for possible funding. Our reactions to potential projects were quite similar, and I approached Kanalu after the panel asking if he would consider working together on a documentary film. Without a second’s hesitation, he said, “yes!”

It took us a while to find a topic and to establish a rhythm in our work – he was teaching full time at the University of Hawai‘i – I was new to Hawai‘i and working as an independent filmmaker. Initially we thought we would make a film about the rebirth of the Hawaiian language. After we did a considerable amount of research on that topic, Kanalu, who loved the Hawaiian language, changed his mind. He felt strongly that we should produce a film about Pidgin English in Hawai‘i, a topic I knew little about. When I asked him why he wanted to change the focus of our film from Hawaiian to Pidgin, this very proud Hawaiian man answered, “Without Pidgin, I would cease to be whole.”

The power of that response struck me, and in fact, we changed the subject of our film to focus on language and identity in Hawai‘i. *Pidgin: The Voice of Hawai‘i* became in many ways Kanalu’s loving homage to the fusion language of Hawai‘i’s working people including Kanalu’s father, George, and many members of his extended family.

Working with Kanalu was wonderful and challenging. Kanalu’s physical condition was always changing. Though we had hoped that he would be able to conduct interviews for the film, he was unable to go on location. He had developed pressure sores and needed to spend

his non-teaching time in bed healing. He held court – and office hours for his students – in his bedroom, and I would meet him there to talk about the film, about Hawaiian history, and about language and identity. He insisted that I sit in on his course, “Hawai‘i: Center of the Pacific,” so I could learn the basics of Hawaiian history and culture. Later, he encouraged me to sit in on his seminar about Hawaiian institutions.

We became friends through his teaching me about Hawai‘i, both formally in his classes and informally as we talked story in his bedroom office.

As Noelani Goodyear-Kā‘opua says in the film, “He saw himself as a student and a teacher at the same time.” He was always learning and teaching.

RR: I would like to ask you a bit about the journey of creating this film:

RR: How long did it take to bring the film from concept to completion?

MB: It took about four years to bring the film from concept to completion.

RR: What were some of the main challenges in bringing it to life?

MB: There were two main challenges in bringing *Kū Kanaka: Stand Tall* to life, and they were in some ways related. The first challenge was finding the funds to make the film. I wrote several grant proposals applying for funding, and I didn’t always succeed the first time around. When I was rejected, it often seemed as though readers of my proposals could not ‘see’ the film I envisioned, and, frankly, it took me a while to see and write persuasively about the film I wanted to make.

The other big challenge was my finding my way through an abundance of materials – interviews with Kanalu, still photos, writings, recollections of family, friends, colleagues, teachers, creative writings – to find a story that felt true to Kanalu. In this journey, Kanalu’s great friend and colleague, Jon Osorio, was a huge help. He knew Kanalu well and he knew Hawaiian history well, and he was able to see – and to help me see – the connections in the life stories of both.

RR: The portrait you present of Kanalu as a teacher, a learner and an activist is unlike anything viewers are likely to have ever seen. What would you like viewers to come away with as far as their deepened understanding of Kanalu’s life and his activism and the ways in which disability was part of that?

MB: I’d like viewers to come away understanding that Kanalu’s activism defined his identity as a Native Hawaiian man with quadriplegia. In the early years following his diving accident, he became a leader in the beginnings of the wheelchair sports movement in Hawai‘i. He loved being part of a group of people whose lives looked like his – he was a beloved member of a large, extended family – and when the Hawaiian Movement grew, he found even more room for himself as a proud Native Hawaiian patriot with a disability. Being both disabled and

Native Hawaiian expanded his life, and he was grateful to see and live in the world through that expanded vision.

RR: Turning to some of your creative choices in the film: In other dominant representations of disability in film, the accident that precipitates a person's disability is often presented very dramatically. For example, in *Me Before You* (2016), when the main character is hit by a motorcycle, the audience is treated to a loud screech, a wide shot of the motorcycle approaching the character, and a medium close-up of the character turning in slow-motion all in a span of a few seconds. *Kū Kanaka: Stand Tall* treats Kanalu's life-changing accident very differently: Kanalu's accident is connected to a shot of a boy diving into the ocean as a calm ukulele track is played in the background. The transition to the details about the aftermath of the accident is signaled by the fading out of the ukulele track and a low, yet soft boom noise. Can you share with readers a little bit about your creative choices here as the director of not presenting the moment of Kanalu's accident in a highly dramatic way?

MB: In deciding to present Kanalu's diving accident the way I did, I was influenced by my friend Katharina Heyer, a wonderful professor of political science and disability studies who dissuaded me from putting Kanalu's accident front and center in the film. Kanalu's diving accident took place in the calm waters of the Pacific – in the same place we see the young divers in the film – and once he hit his head, it took his young friends a while to understand that he had been injured. The accident changed Kanalu's life forever, but he understood it as both a sudden, dramatic change and a change which took years to assimilate. In his own life, his disability was a fact because Kanalu's disability was visible; he didn't need to talk about it. For him, I think, his accident meant loss, acceptance, and assimilation to a new identity. His ability to assimilate newness, not just in identity but in ideas too, made him a person open to all kinds of people, ideas, and approaches to living. To have overdramatized his accident would have misrepresented who Kanalu was.

RR: Were there any other aspects of his life that you set out to consciously present differently from how disability is frequently presented in film and media? (Perhaps including some things that are frequently overlooked or ignored and perhaps excluding others?)

MB: Because Kanalu's disability was visible he did not need to talk about it. You knew upon seeing him that he was in a wheelchair. Seeing Kanalu physically made an impact. When he entered a room in his electric wheelchair, you heard him coming. Once you saw him, you saw him expertly maneuver his chair. If he was part of a presentation that called for the Hawaiian protocol of chanting, it was his voice that drew your attention. If you heard him lecture, you paid attention to his eloquence and speaking voice and to his wit. There was so much about Kanalu that was large and broad. Disability was one of those things.

If I'd known before he passed away that I would be making a film about him, I would have filmed him more with other people. He commanded a group, not by assuming control but because other people looked to him to lead. He was smart, kind, compassionate, funny,

stubborn, honest, and fair. Though he occasionally nodded off – don't we all? – to be in his presence was to be with someone alive on all burners. He was alert to other people, and he always listened in a way that let you know you had been heard.

RR: Can you speak a bit to the ways in which Kanalu connected his own embodied experience with the native Hawaiian experience?

MB: Kanalu felt that if he, a man in a wheelchair, could be an activist, so could anyone. I'm paraphrasing here, but he once spoke of language and history as weapons in a war for cultural survival. At the same time, he also spoke of the Hawaiian movement as being broken and in need of repair, and he compared himself to that. He felt he understood Hawaiian trauma in his being since both he and his nation had suffered trauma and emerged with an identity tempered but with resilience. As Jon Osorio says in the film, "the kind of trauma imposed on our people could be compared to the trauma of Kanalu's accident. You could say that it really changed the trajectory of where we were headed as a nation, as a people." Of course, Kanalu's accident changed his trajectory too, and he would have argued it was that change that made him who he was.

RR: Thinking about your own larger practice as an artist and teacher (and perhaps your own mission(s) in your work), how do you place your film *Kū Kanaka: Stand Tall* within this?

MB: I learned from Kanalu in making *Kū Kanaka: Stand Tall* that there are embodied languages, every bit as eloquent as those we speak. I like to tell stories. All my films in some way deal with language, identity, and stories of extraordinary people whom we may often overlook. *Kū Kanaka: Stand Tall* taught me through Kanalu's story, that identity is complex, multi-dimensional and, in the best case, expansive.

RR: Is there anything else you would like to add about the film?

MB: Kanalu was someone who, though he loved being on stage, did not like to call attention to his accomplishments. He drew a distinction between American rugged individualism and what he called Hawaiian rugged groupism. He loved that groupism and understood that not only his life but his sense of himself depended on it. Without his family, his students, and his Hawaiian community, he would not have been able to recover and move forward with confidence. He felt that his accomplishments--and they were many--came about not by his effort alone but by the constant embrace of those who knew he acted not for self-aggrandizement but for the betterment of all.

RR: Any upcoming/current project(s) you are most excited about that you would like to mention?

MB: At the moment I'm busy working on getting *Kū Kanaka: Stand Tall* into classrooms and other settings where people with stories similar to Kanalu's can use it. Within reason, I'm happy to go anywhere to speak about Kanalu and the film.

For institutions subscribing to Kanopy, *Kū Kanaka: Stand Tall* is available at the following link: <http://www.kanopy.com/product/stand-tall-ku-kanaka>

The DVD of *Kū Kanaka: Stand Tall* and streaming options are also available at New Day Films: <https://www.newday.com/film/k%C5%AB-kanakastand-tall>

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Notes from the Field

Call for Proposals - CONNECT #PacRim2020

Genesis Leong

University of Hawai'i at Mānoa, Center on Disability Studies
Hawai'i, United States


The University of Hawai'i at Mānoa, Center on Disability Studies, in the College of Education, is accepting presentation proposals to be featured at the 35th Annual Pacific Rim International Conference on Disability & Diversity at the Hawai'i Convention Center, March 2–3, 2020. Submissions are being accepted from June 1, 2019–December 1, 2019 at www.pacrim.hawaii.edu.

The theme of the conference is **CONNECT to Create Opportunities**. Pac Rim 2020 will connect individuals in the field of disabilities, to build relationships and partnerships between Hawai'i and the global community.

Pac Rim 2020 will feature presentations that showcase best practice, research, and community policies & planning to improve outcomes for individuals with disabilities. Presentation formats include: 2-hour poster presentations, 30-minute shared presentations, 60-minute breakout presentations, multi-hour interactive workshops, keynote speakers, and much more. Conference topics include:

- **INCLUSION** An inclusive community promotes and sustains a sense of belonging; it values and practices respect for the talents, beliefs, backgrounds, and ways of living of its members.
- **EMPLOYMENT** Employers and human resources staff need help understanding reasonable accommodations, and expectations for employment must be raised through specific training and supports.
- **HEALTH & WELLBEING** A balanced lifestyle and optimal health is a goal for us all throughout our lives. At-risk groups have difficulty finding balance because the focus may be on disability and not on holistic and healthy lifestyle.
- **POSTSECONDARY EDUCATION** Many factors influence a successful transition, these include the type and severity of impairment, environmental barriers and supports, personal characteristics, socioeconomic status, and expectations.
- **PRE-K to GRADE 12 EDUCATION** With shortages of certified special education teachers, inappropriate student-to-teacher ratios, and classrooms with diverse-needs, students don't always receive the necessary individualized supports to facilitate their learning, development, and transitions.

To register for #PacRim2020 Early Bird Registration, visit www.pacrim.hawaii.edu or contact prreg@hawaii.edu, call 808-956-8816, or fax 808-956-4437.

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Dissertation Abstracts

Compiled by Jonathon Erlen, University of Pittsburgh

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Surviving and Thriving: An Integrated Critical Theory of Chronic Pain from Stories of Urban American Indians Living with Chronic Pain. Duwe, E. A. G. ProQuest Dissertations & Theses, 2016. [Ph.D. Dissertation] United States: Illinois: University of Illinois at Urbana-Champaign. Publication Number: 10609649

Muslim and Catholic Perspectives on Disability in the Contemporary Context of Turkey: A Proposal for Muslim-Christian Dialogue. Ilgit, A. ProQuest Dissertations & Theses, 2017. [S.T.D. Dissertation] United States: Massachusetts: Boston College. Publication Number: 10284375

Voices at the Intersection: Exploring the Roles of Race and Gender in the Pedagogies of Black Male Special Educators. Fenton, P. E. ProQuest Dissertations & Theses, 2017. [Ph.D. Dissertation] United States: Florida: University of Miami. Publication Number: 10269515